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MEANINGS OF DEAFNESS

by

David Hugh Leishman Moorhead

A thesis submitted to the University of Bristol

in accordance with the requirements of the degree of PhD

in the Faculty of Social Science

Department of Social Work

in September 1995.

Abstract

This thesis investigates the ways that different groups of people may perceive the experience of deafness. It explores the nature of power in relationships between these groups, and the way people may or may not be able to exercise control over the circumstances of their lives. It studies the nature and origins of challenges to traditional ways of understanding deafness, which see it as a loss, which pathologise the experience of those who are deaf, and place responsibility for alleviation and management with individuals.

It places the experience of deaf people at the centre of the study and uses their accounts, with those of people who work with them in the personal social services, to create a framework for understanding the experience of deafness and to uncover issues for further investigation. It describes the development of a methodology to use in this form of investigation which values people's own perceptions and experience above imposed meanings and adopted certainties.

It outlines a framework that arises from this form of analysis of people's accounts, and sets out a commentary which explores issues about identity, challenge, voices, languages, separation, denial, acknowledgement, help and power. It suggests how this framework can be used to look at ways that deaf people experience deafness, how deaf and hearing people interact with one another in mediating relationships, and how power and control are exercised in these.

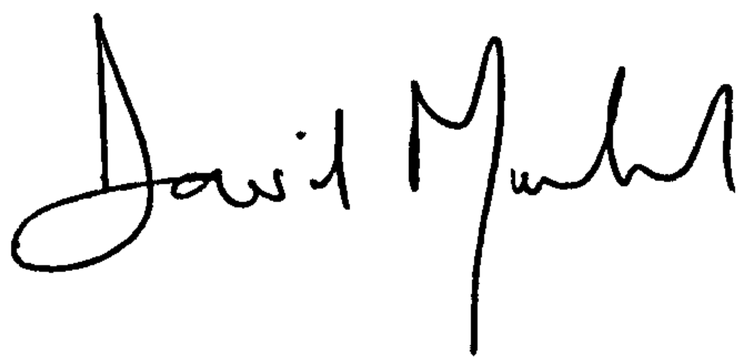
It looks at similarities as well as differences in people's experiences, and how similarities with other marginalised and oppressed groups of people place deaf people and their experience on a wider political and humanitarian context.

Author's Declaration

This thesis was written by the author and derives from work carried out on a research project funded by the Leverhulme Trust.

The research was carried out by the author and by Sheila Moon, who is Deaf and was specifically employed to interview Deaf participants and to bring a Deaf perspective to the conduct of the research.

Her contribution to the research project accords with the aims of the research and with its methodology and was significant in enabling the author to develop his perspective and understanding.



David Moorhead

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PART 1

THE PROCESSES

CHAPTER 1

RATIONALE

I will start my thesis at the end. My research has led me to two conclusions, which are these :

Deaf people know about deafness

Deaf people are human

These are simple statements; they seem to be unarguable and to contain self-evident truths. So, why do we, as hearing or deaf people, need to make them? And why do we need to engage in the questioning process through which these conclusions have been reached? We need to because they present an image of deafness and deaf people that is often at variance with notions of deafness held by hearing people, and with deaf people's actual experience of acknowledgement and equality.

This thesis describes what these conclusions mean, what kind of questions were posed to reach them, and why both the questioning process and the conclusions are important.

Research focus and processes

The study is called 'Meanings of Deafness'. This choice of title is deliberate. I have lost count of the number of times it has been misconstrued as 'The Meaning of Deafness' or 'The Meanings of Deafness'. Pluralising 'meaning' reflects my contention that there are many different ways of talking about deafness because there are many different experiences of it. Omitting the definite article is intended to

challenge the widely-held notion that there is, or should be, a definitive understanding of deafness and that this determines the way we arrange our contact with people who are deaf.

The title is also intended to indicate the nature of this study, which is not designed to answer specific questions. The search for answers, of which the need for a definitive notion of deafness is an indicator, may show more than anything else that it is not *answers* that are needed at this moment in time to develop understandings of deafness and the experience of deaf people, but *questions*. This research explores what kind of questions may need to be asked, why, and how they can be.

So this study has two central elements. One deals with the research question, which is about identity: the way people construct their sense of who they are and the forces and circumstances that influence this process. The other looks at how to investigate this and how to give value to, and derive understanding from, people's own accounts of this process of self identification.

The context of the study

What is the context from which these elements arise?

Firstly, there is the context of accepted knowledge and received understandings about deafness and the experience of deaf people. These are being challenged by changing social, economic and political circumstances and by the realignment of relationships between individuals and groups of people occurring in a late modern age.

Much of our present-day understanding of deafness and the experience of deaf people is based on the perception of deafness as a sensory loss.

Definitions are based around the mechanics of developing or not acquiring

speech, and are framed in terms of decibel loss (Myklebust, 1964). They focus on hearing and not hearing sound and on the degree to which this occurs and at what age (Sainsbury, 1986). The consequences are seen as individual and to impair intellectual and emotional development (Ballantyne, 1977).

Causes are seen as physiological in nature, whether hereditary or as a result of illness, accident or age (Ballantyne, 1977; Myklebust, 1964) while effects are seen largely as functional (Sainsbury, 1986; Levine, 1964) and in terms of the individual's, or his or her family's adjustment to the loss. Indeed, as Kyle and Pullen (1988) point out, the use of language to describe deafness focuses on the lack of functions; "hearing *impairment*", "deaf *without* speech", "*partially* hearing", "hearing *loss*", (my emphasis).

The perspective from which these definitions are created is largely that of people who have experienced hearing. To a person who has never heard, the concept of hearing has a different meaning. Consequently, to this group of people the concept of deafness has a different meaning as well.

Deafness then is seen as individual in cause and effect, describing a handicapping condition and deriving from a hearing perspective which sees deafness as a single state, emphasising *loss* of hearing as the key element.

These accounts of deafness accord with the current general view of disability as a loss of function or ability, and centre the experience of deafness within this framework. This view derives primarily from a biomedical perspective, which is currently being challenged by the perspectives of disabled people.

Attitude studies consistently identify negative features as characterising people's perceptions of disability and of people with disabilities. These include

dependence, isolation, depression, emotional instability and social inadequacy (Yuker *et al*, 1960; Altman, 1981). These findings are mirrored in studies of people's attitudes to deaf people and deafness, and seemingly in the perceptions of deaf people themselves (Bunting, 1981; Furnham and Lane, 1984).

Services to people with disabilities are seen in terms of rehabilitation. This is determined by paradigms of cure, alleviation and adjustment, and tends to address the negative features identified above. Because the norm against which disability and people with disabilities are measured is about being able-bodied, then the failure to achieve this, by however small a margin, will mean that people with disabilities continue to be seen as dependent, isolated, depressed, emotionally unstable and socially inadequate, and therefore in continuing need of care and treatment to help them adjust to *their* handicap.

What effect might this continuous emphasis on individualised negative characteristics have on people's senses of who they are? Are these negative characteristics institutionalised into the frameworks for understanding disability and deafness? And if so, what features of our current practice in personal social services may reflect these institutionalised understandings and so deny people who are deaf their sense of who they are and control over the circumstances of their lives that allow them to assert their identities? What marginalises people and denies them opportunities to enter into reciprocal relationships with their hearing peers?

Increasingly, disabled people are arguing for full participation in society. Several writers in the UK are critical of the individual loss-focused model of disability which they argue prevents people from achieving these aspirations (Oliver, 1983; Finkelstein, 1981; Abberley, 1987). These social theorists of disability attempt to

derive their analysis from the perspective of people with disabilities, and from the social experience of disability.

Turning specifically to issues about deafness, there are indications in research reports, in professional experience and in the perspectives of deaf writers, that the way of working that arises from an individual loss-focused approach, and from a frame-work which continues to emphasise the negative features of deaf people's experience, no longer addresses deaf people's desire to participate equally and fully in society, or to allow them to explain their deaf experience in other than negative ways (Ladd, 1988; Kyle and Pullen, 1988). Furthermore, they argue that this way of working and the perspective from which it derives, specifically denies them the opportunity to centre their explanations of deafness on their own cultural experiences and denies them the ability to use their own language to do this.

Writers in the field of deafness are attempting to widen the context within which deafness is placed (Taylor, 1986; Ladd, 1988; Kyle, 1986). They are seeking to link deaf people's experiences to those of members of other oppressed and disadvantaged groups, to understand more fully the nature of deaf people's oppression and to see how an analysis in this broader context can help deaf people's aspiration to fuller participation in society. Their work owes much to the emancipatory perspectives of gender and of race which challenge narrow androcentric and ethnocentric views, and it incorporates the experiences of deaf people into understandings of deafness, placing research, enquiry and discussion in the same location as the people who are the subject of it (Harding, 1987; Jones and Pullen, 1992).

There is also a growing community influence in the lives of deaf people which is related to the growing awareness of the demand for self-determination by people

who see themselves as culturally rather than audiologically deaf, and increasing public acknowledgment of their capacity to achieve it. This overt assertion of a shared cultural identity and the sense of community connected to it, derives significantly from the increased legitimisation of British Sign Language (Kyle, 1986). Other groups of deaf people, such as deafened people and those for whom spoken English is their first language, are also asserting their sense of a different common identity (Corker, 1990) and may be taking a lead from Deaf people in this respect.

Additionally there is a repositioning of the institutions of social welfare as they affect deaf people, and a re-examination of their role in deaf people's lives. Local authorities have experienced widespread problems in the development, management and delivery of social work services to deaf people. These problems seem to be common to all local authorities (Social Services Inspectorate, 1988). Problems of recruitment of social workers have been identified (Peckford and Hawcroft, 1986; ADSS, 1986). Recent developments in social policy, in particular care in the community, and current reviews of welfare across the whole political spectrum, have brought about a rethinking of relationships between service users and service providers and a re-examination of needs and provisions and of rights of consumers and citizens. A number of local authorities are seeking to apply principles of equal opportunities across the whole range of communities and groups of people who use their services, including disabled people and deaf people.

These developments set out a context where traditional assumptions about deafness and about the relationship between deaf and hearing people are being challenged. Indeed, there is a diversification of relationships as individuals and groups assert their difference and their desire for connection, sharing, belonging and inclu-

sion. Traditional assumptions about the meaning of deafness and the relationships that are created out of these seem unable to meet this new test of validity which is directly connected to people's aspiration to social justice and equality.

This diversification, and the deconstruction of meanings that takes place as a result of it, is happening in one part of a wider stage on which individuals, groups and communities are shedding old certainties and coming to terms with new relationships, in a much wider range of social, economic and political circumstances than has existed before (Giddens, 1990). It is from this context that my research questions arise.

So, what are the research questions, and how have they been developed?

Professional experience and personal significance

The starting point for this process is contained in a series of questions I have put to myself during the course of my professional practice as a social worker:

Why is there always a gap between what I offer as a social worker and what deaf people seem to want and need? ..

Why are deaf people not able to articulate their needs and wants?

Why does there always seem to be a tension between what I think deaf people need, what my employers are prepared to offer, and what deaf people want?

Imposed meanings and power relationships

These questions raise issues about power, meaning and relationships. They arise not only from my professional experience of working in social welfare with people who are deaf, but also from my personal experiences of family, class, race,

and gender. They suggest that powerlessness is not confined to deaf people, that people's experiences are not being acknowledged and that traditional ways of understanding deafness are inadequate to the task of illumination.

They reflect my dissatisfaction with the nature of my social work practice with deaf people, and my disillusion with its relevance and effectiveness. But they also indicate my desire to challenge the adopted certainties I use to construct my meanings of the world and of relationships between people in it. In doing this research I wanted to look at my direct experience of exerting power in the lives of others and at why, by and large, I did not seem to understand how or why I was doing this. This study looks at ways of breaking out of cycles of ignorance, and of letting go of some of the old certainties and assumptions about relationships and power, and this comes out of my wish to challenge my own ignorance and to try and understand the nature of my oppression of deaf people.

This thesis, then, has overwhelming personal significance for me and I have used this personal significance to adopt a reflective approach in the research. This influences the choice of approach, subject matter, methodology, and the way I have interacted with the material that is presented to me in people's accounts.

This personal significance means that I cannot obscure, in Sandra Harding's phrase, "the context of discovery and the context of justification" (Harding, 1987). Making these overt is a key part of the research process. By describing them, and my place in them, I open up new ways of understanding the experience of deaf people, and the nature of the relationships they have with others by revealing issues about power, acknowledgement and dependence that existing ways may be unable to grasp.

This leads me to ways of thinking about the work, of doing it, and of writing

about it which ask me to question my assumptions and attitudes and to lay aside my adopted certainties, in order to reflect on, acknowledge and accommodate different ones.

The release of certainty is challenging, exhilarating and empowering - and the source of tension, anxiety and fear. These features are interconnected, and create the strength of the reflective approach. Challenge cannot be sustained without anxiety, nor empowerment without tension and fear.

Social workers with deaf people operate in an area of work where traditionally certain aspects of personal experience are given high value. Services are focused, by and large, on single providers and so are highly personalised (Moorhead, 1990). Features of this personalised service are **commitment** (in terms of willingness to work in a variety of roles and settings, but without regard for conflicts of interest or differences in power); **the ability to communicate** (in terms of the exclusive use of a method of communication, rather than the use and knowledge of someone else's language); and **specialist knowledge** (in terms of knowing things that offset the ignorance or disinterest of others, but not to challenge it).

Value is accorded to these features in different ways. It is accorded, passively, by deaf people who are seen as dependent on these key workers for their connections with the wider community in which they live and work. It is accorded by local authorities and other public agencies of welfare who are only able to accept the validity of deaf people's experience when it is mediated through people who share the same professional and cultural ethos. It is accorded by other agencies and professionals who do not challenge the power of specialist knowledge as long as it does not challenge theirs.

Yet the experience of people who are deaf is consistently ignored or undervalued, except, seemingly, when it corresponds with the meanings of deafness that we have created and accorded to it. Indeed, if our *authentic* experience leads us or deaf people, to challenge this received knowledge, there are few opportunities for this challenge to be expressed, or for the authentic experience to be acknowledged.

Is this exclusion acceptable to any notions of social justice and equality? I think not. Firstly, any understanding of deafness that excludes or undervalues the experience of deaf people will be incomplete. The assumption that all human experience is the same, regardless of the perspective of the person living it, has been exposed as false by feminists. It is constantly challenged by Black people, gay men and lesbian women, disabled people and poor people as denying different experiences of gender, race, sexuality, physical ability and economic power. Further, it denies the existence of power relationships that determine the status of different groups of people in society. This power may be political, moral, economic, or based on class, gender and race (Rutherford, 1990; Centre for Contemporary Cultural Studies, 1982).

Secondly, if we continue to define deafness and the experience of deaf people only in terms of our own covert perspectives and without acknowledging differences in power between groups of people, we will continue to impose our meanings of deafness on this group, and deny them theirs. This has significant dangers not only for deaf people but also for ourselves. If we are not prepared to challenge the basis of the meanings we impose on deaf people, we risk denying not only deaf people's identity and their right to assert it in terms of their own different experience, but also their entitlement to the same range of human rights that we enjoy ourselves. We may also, by implication, be inviting other groups more powerful than ourselves to do the

same to us.

So, we can see the experience of deaf people as a challenge to our ways of understanding deafness, to our notions of social justice and equality and to our own experience of dependence and powerlessness. These challenges make us question the certainties we have adopted to construct our picture of the world and the people in it; they make us confront our oppression of others and why we do it; and they make us aware of the oppression we ourselves suffer. This is difficult for us, so we may resist the challenge. It is also difficult for the institutions of a powerful state, so the state may encourage us to resist it by placing us into structures that purport to encourage the promotion of social justice and to empower people, but which in reality merely serve to sustain existing power relationships through welfare services that are characterised by notions of passive dependence and helplessness.

To understand this we need to look at the way power is wielded in helping relationships of this kind, by whom and with what effect. This means looking at inequalities of power, and how far and in what circumstances people are able to exert their own power to assert what they need in order to be the people they are. It means, crucially, understanding the nature of other people's own perceptions of their reality and how and why this may be different from our own.

> *"To create needs is to create discontent and to invite disillusionment. It is to play with lives and hopes. The only safeguard in this dangerous game is the democratic requirement of informed consent. One has no right to speak for needs which those one represents cannot intelligibly recognise as their own."* (Ignatieff, 1984).

So, the research rationale has developed around issues of social justice and equality, the political nature of personal experience and the need to find ways of valuing and including people's own accounts of their experience, to help inform us about it, and

how we can interact with them. How does this developing rationale translate into everyday reasons for doing the research?

Knowledge, exclusion and empowerment

Firstly, the research addresses issues about knowledge. It is most likely that the level of understanding about deafness is much lower than has previously been assumed. Knowledge is limited because the partial perspectives we have adopted exclude the experiences of deaf people, and restrict our ability to ask the right questions. A first major purpose of the research is to seek to broaden the base of knowledge about deafness by identifying some of the issues that can be asked and some of the issues that can be explored by revealing the understandings and perceptions of deaf people with different linguistic, cultural, social and audiological experiences, and to look at those of professionals who work with them.

This analysis reflects a post-modernist theoretical framework, developed by Foucault and Giddens, amongst others, and by discourse theory, but does not derive from these sources. My analysis and understanding has developed primarily from feminist analysis, drawing attention to the way that feminists question structures, meanings and explanations that derive from exclusive, single-gender experiences.

Secondly, the research addresses one of the original core questions, about why deaf people are not able to articulate their needs and wants. As Michael Ignatieff asks:

> *" ... when is it right to speak for the needs of strangers? Politics is not only the art of representing the needs of strangers; it is also the perilous business of speaking on behalf of needs which strangers have had no chance to articulate on their own."* (Ignatieff, 1984)

As I have outlined above, this seems likely to be the case because people's accounts

of their experience are not listened to or paid attention to, nor are people accorded dignity and respect. These accounts are largely not incorporated into our understandings of deafness, nor into the structures of welfare that are created to administer support for people's perceived needs. A second major theme in the research is to try and develop a methodology and a philosophy that respects people's different use of language and their different social experiences and which enables people to give their accounts in their own way.

Thirdly, the research considers the implications of increased understanding of the nature of relationships between deaf and hearing people and of the different levels of power which exist in them, for the way that deaf people are able to fulfil their aspirations and have their needs met by the services that have been created to administer to them. A third major theme, then, is about deaf people's empowerment and the opportunities for or restrictions on deaf people entering into reciprocal social and political relationships with others and the effect this has on their ability to exercise moral power in their lives.

The use of language is central to these themes, and the study looks at a number of issues connected with it.

It considers the issue of language and meaning, and how people are able to describe their experiences and have them acknowledged. It focuses on how to use people's reports of their own experience as the basis for the parameters of our understanding.

It looks at the issue of language and power and, specifically, at how two languages may or may not be combined in the research study, where imbalances in people's opportunities to use their own language, and restrictions on the circumstances

in which they can do this, affect the meanings they are able to create and influence.

It looks at the issue of language and communication, how these are perceived as means or ends, and how we connect these processes to relationships between people rather than just service structures and provisions.

Research questions

These themes lead to the research questions being put as follows:

- How do different groups of people understand deafness and the experience of people who are deaf?
- How might any differences or similarities arise?
- What effect might any differences or similarities have on the way deaf people are given and receive services?

CHAPTER 2

ISSUES ABOUT METHODOLOGY

Choosing methods and methodologies

In the previous chapter, I set out the rationale for this study, outlining the reasons why I decided to do the research and the contexts from which these reasons arose. In this chapter, I will elaborate on the rationale and philosophy and describe issues about methodology. This will show why I chose to investigate the research questions in the way that I did.

This study is taking a different look at ways of understanding deafness and the experience of deaf people. It hopes to reveal new contexts of explanation, partly because a number of different groups of people, including myself and some of my professional colleagues, find the current contexts inadequate to our needs for explanation. It is also partly because these contexts seem unfair, being based on narrow, implicit understandings and excluding the perspectives of deaf people.

In order to reveal these new contexts, I needed to decide if it was appropriate to use existing methods of enquiry and research methodologies, or whether the current contexts of explanation were in part created by the way information was collected and questions asked. I believe the latter to be the case and I describe here how I came to this conclusion and the sources I used to guide me to it.

One of these sources was my analysis of a number of recent research studies in the UK which have looked at the experience of deaf people. This showed that deafness was still defined, to a great extent, in audiological terms, rather than in terms of language and social experience. It also confirmed that different aspects of people's

experience - their gender, class or race - were often overlooked, or not accorded value and meaning (Appendix 1).

So, I have an additional purpose in looking at issues on methodology, and this is to develop new rationales of investigation and discovery. This runs alongside the need to describe a methodology to do the study.

This duality of purpose creates tensions and the existence of tensions is one of the central features of the research project. It also means that I cannot rely, to the same extent as other researchers may be able to do, on an established methodology as a central anchor around which I can organise my study, especially in deciding what method of enquiry to use, how to analyse the findings and how to put together an explanation of them.

As a result, I need to create my own central organising mechanism to help me to do the research and to give it academic and political validity. I have sought to do this by creating an unity at the heart of the research, a consistency between the reasons I have chosen to do what I have done **(the research philosophy and rationale)**, what I have chosen to study **(subject matter and research questions)** and the way I have chosen to do this **(the method of enquiry)**.

Creating and trying to manage this consistency has two consequences. On the one hand, I can develop my working methodology using this unity as a guide and I can investigate issues without having to rely on an approach that may predetermine the questions I ask and the way I ask them. It provides an integrity and a perspective which accords with principles of social justice and equality - of inclusion, connection and respect for difference - and validates it in the eyes of others. This makes the information from people's accounts legitimate and gives it authority and authenticity.

On the other hand, however, it creates enormous uncertainty. I have abandoned a key external certainty, that of an established and accepted methodology, in order to create the circumstances that allow new questions to arise. This is very liberating, but can also undermine my own confidence and make me doubt the very ideas I am trying to develop. This tension is largely inevitable and necessary, but can be very difficult to bear over a long period of time. Two extracts from my work diary may help to illustrate this. The first was written in the week before the start of the fieldwork, and second on the day after it started.

> *"I am feeling utterly alone. I am frightened, insecure and feel not able to do the work ahead. I feel as if I have not prepared properly, I have not thought through what we are going to do, and do not have the skills or the ability to carry this project out. I feel as if this is a worthwhile, important and potentially very influential research project - and I couldn't care less.*
>
> *"I feel as if I am a con. That people have an enormous amount of incredibly misplaced confidence in my abilities and in my qualifications to do this.*
>
> *"I am not looking forward to next week. I do not think I will be able to conduct any interviews well, and feel I will let down a large number of people.*
>
> *"I feel totally helpless and powerless". (4/4/91)*
>
> *"My mind is starting to work again. And the thing is starting to click.*
>
> *"I still have a slightly unreal feeling, partly worrying about what we are <u>not</u> going to get, and partly, I think, about what we <u>are</u> going to get. For all my anticipations, and my dreams of challenging, original and constructive outcomes, there is still within me an abiding sense of uncertainty, of not quite knowing what will come up. That sense of uncertainty is vital. I am not used to feeling that uncertainty as positive; it <u>is</u> in this case, because it shows that we are not anticipating and constructing our study on <u>our</u> perceived certainties". (8/4/91)*

I have been unsure exactly how to describe issues about methodology, partly because of the duality in my treatment of them. What I will attempt to do is to describe the main features, and some of the ways these interact.

Firstly, there is the status and value of personal accounts. Recent work in medical sociology (Cornwell, 1988; Stainton- Rogers, 1991; Beattie, 1993) has looked at how understandings of health can be informed by people's accounts and how people construct them. Feminist methodology (Harding, 1987; Gilligan, 1982) has revealed the distinctions between women's and men's voices and the centrality of women's experience in determining new theoretical and empirical resources, by emphasising the validity of women's accounts.

This emphasis on personal experience includes the way in which I bring my own experience into interaction with that of participants and in the way, for example, that I react to the uncertainty and tensions implicit in the study. This reflective approach forms part of the 'studying-up' dimension that feminist enquiry has in common with other forms of emancipatory studies (Harding, 1987; Abberley, 1988).

Secondly, there is the status of the study. This study is looking at how to set out a framework that allows questions to be asked - and new questions to be identified - and at how we can understand the mechanics of people's experiences in terms of their structural as well as their personal influences. It is not looking to provide answers, or even new theoretical frameworks within which answers can be located, but rather to come up with new descriptions (Hammersley, 1990).

Thirdly, there is the acknowledgement of tensions. As we will see, people's accounts contain a multitude of issues, some of which appear contradictory and self-denying. Issues have different origins and derive from different sources, and tensions often arise when these different sources are not acknowledged. These tensions may manifest themselves in people's anger or sadness or assertiveness but will often reflect

the challenge that people present to meanings of their experience imposed on them by others and others' failure to acknowledge the meaning of their own realities.

This imbalance in power and control is reflected in the research process itself. At the centre of the research philosophy is the importance of principles of social justice and equality, both in forming ideas about the subject matter for research and in carrying it out. The focus in this study is deafness and the experience of deaf people. Yet I am hearing. How do I, or can I, justify my doing this research?

I believe I can do it by elaborating the "context of justification" (Harding, 1987) in relation to *my* reasons for doing the research and the personal and political nature of these reasons. I also do it by acknowledging the contradiction and the tension it creates. This provides me with opportunities to find ways of addressing inequalities such as incorporating a Deaf perspective into the Project Advisory Group and by appointing a Deaf researcher, one of whose primary tasks was to bring the challenge of that perspective directly into the research process.

Even so, inequalities have persisted. For example, there has been a difference in status between myself as primary researcher and my Deaf colleague as assistant, who worked part-time on a lower salary scale and who had less influence on the development of the project. On the other hand, my working relationship with her helped me to understand aspects of the nature of my oppression of deaf people in ways that no amount of reading or external consultation could ever have done.

Fourthly, there is the importance of significant sources. This relates to the role that these have in the lives of participants in all three groups, the nature of these sources and the effect of there being only a limited number of them.

Fifthly, there is the influence of serendipity. Luck and fate have a part to play

in any form of discovery. I distinguish between luck - or serendipity - and fate which is more connected to notions of powerlessness and passivity. As will be seen, these are also major elements in people's accounts.

Sixthly, there is the acknowledgement of context. A major element in my own attempt to deconstruct my meanings is my acknowledgment of the structural features of my understanding: my gender, my race and culture and my class. Identifying these features helps to show me where some of the root causes for my ignorance and oppression may be, and also shows me the places I can go for guidance and illumination.

Personal Accounts

> *"Do I contradict myself?*
> *Very well, I contradict myself*
> *(I am large, I contain multitudes)"* (Walt Whitman, *"Song of Myself"*)

First of all then, let me look at personal accounts. I have chosen to use participants' accounts of their experience of deafness as the primary source of information for my attempt to uncover meanings. It is my personal experience that has led me to frame the research questions and to do the research in the first place. Part of the motivation to do this has arisen from my perception that deaf people's accounts of their experience have often been omitted from official descriptions, explanation, and understandings and have been devalued and ignored. I am using my experience, my personal accounts, to engage with that of participants, and my interaction with their information gives me insight into commonalities and differences in experiences.

What are the issues for me in using personal accounts? These are concerned with validity and authenticity, with collection and with understanding.

The quotation from Whitman highlights key elements about personal accounts. People are complex beings and they have many accounts. In recent years, medical sociology has focused on lay accounts of health, as distinct from official or professional accounts, in an attempt to widen the debate about health, about who owns it and who decides about it. This work suggests that people's accounts of the world, and their attempt to produce understandings for themselves, are diverse, that people use a variety of 'texts' and move from one to another in their story-making (Stainton-Rogers, 1991). It also proposes that people are likely to give different stories to different people in different circumstances (Cornwell, 1984).

This means that within the framework of 'objective' study, which uses scientific enquiry as a model, personal accounts are subjective and open to many interpretations and are therefore unreliable. Personal histories, anecdotal accounts, people's stories, all become viewed as sources of 'soft' knowledge, information that provides colour, shade or detail, but not form or structure (Zelditch, 1982).

For others, it is this very diversity and the tensions created by contradictions within and between people's accounts, that create opportunities for study:

> *"Not only do our gender experiences vary across the cultural categories; they also are often in conflict in any one individual's experience."* (Harding, 1987)

Harding suggests that these "fault lines", as Dorothy Smith terms them, are a rich source of insight, especially for feminists. Stainton-Rogers agrees:

> *"I found particularly useful Mulkay's (1991) argument that this idea of 'text' is a liberation from the conceptual wild goose chase after validity, and means that you can ask more interesting questions, like what conduct does a particular text prescribe or warrant, or what ideology is it peddling?"* (Stainton-Rogers, 1991)

Personal accounts can also give us something that is largely missing from unelaborated

explanations and understandings that may be based on specific ethnocentric and androcentric perspectives. They provide, as Harding points out, the opportunities to move away from the partial definitions of experience that derive from these perspectives:

> *"Defining what is in need of scientific explanation only from the perspective of bourgeois, ... white men's experiences leads to partial and ... even perverse understandings of social life."* (Harding, 1987)

It is women's accounts of their experiences which are the 'reality' against which hypotheses about these experiences are tested. There seems no reason why this cannot equally apply to deaf people.

So, the validity of personal accounts and their use in the study, derives from three sources: firstly, from their diversity and the opportunities this provides for study and questioning; secondly, from the purpose of the study, which is concerned with finding questions to ask, rather then answers to be given; and thirdly, from the challenge that they make to partial definitions and understandings and their contribution to unravelling the basis for these. This is not only 'good' for enquiry but also accords with principles of equality and social justice - why should anyone's or any group's experiences be excluded or devalued?

Their authenticity can be measured, I would suggest, by the fact that people were prepared to give them in the first place and to reveal so much about themselves in them. One of the key features in participants' experience of deafness is their desire for acknowledgement, and being able to give their account is a crucial first step to achieving this. Often, this is the first time that people have done this and this reveals issues to them as well as to me.

The second issue relates to the collection of accounts. If I have decided, as

in this study, that participants' accounts are the source for questions and issues about understanding deafness and my oppression of deaf people, can *I* collect these accounts? Harding argues that it is for *women* to reveal what women's experiences are, that a central feature of feminist methodology is that it is for women (Harding, 1987). These arguments are being pursued by Deaf and hearing researchers in the study of deafness (Kyle and Pullen, 1988; Jones and Pullen, 1992; Baker-Shenk and Kyle, 1990).

This comes back to the core tension in the unity of the research to which I referred earlier. Yet my purpose is not primarily to reveal deaf people's experience. It is, rather, to look into deaf people's experience to understand better the nature and origins of my oppression of them and to seek their help in doing this.

However, part of the validity of personal accounts comes from the fact that they belong to the people who give them and that an important element of that ownership is that they are private. Cornwell (1988) suggests that people are more likely to provide private accounts in circumstances of shared cultural and linguistic experience. Moreover, principles of equality suggest that people should be given the opportunity to provide their accounts in circumstances that are equitable and that these accounts are more likely to be clearly theirs if this is the case. This means that an essential feature in the process of collection is that people are free to give their accounts in circumstances where and with people with whom they feel comfortable and in relationships of respect and reciprocity.

The third issue concerns ways of understanding people's accounts and the kind of conclusions that can and cannot be drawn from them. This clearly relates to the purpose of the study and to having respect for the information people give. This means being especially aware of the tensions created by a reflective approach, taking

care that my interaction with people's accounts

does not lead me to impose *my* structure and *my* meanings onto their experience.

These tensions are partly resolved by my being clear about the purpose of the research and that this is contained in the unity which organises the work. As I have pointed out above, my purpose is to try and understand the nature of my oppression of deaf people through their experiences, and to do this I need to respect people's accounts and to acknowledge their experiences as authentic in their own right.

They are also partly resolved by the fact of the reflective approach creating new opportunities to think about and view deaf people's experience, particularly in terms of their gender, race and culture. This provides new ways in which to understand deafness but also, more importantly, acknowledges the other experiences that deaf people have - as women, as Black people, as single parents, as middle class, as being gay or lesbian, as being employed, as poor.

The nature of the study

> *"Both authorised and anecdotal literature have created too many stories about Negroes to be suppressed. But putting them all together does not help us in our real task, which is to disclose their mechanics. What matters for us is not to collect facts and behaviour, but to find their meaning."* (Franz Fanon, *Black Skin White Masks!*)

As I have indicated earlier, this research addresses my ignorance and the nature of my oppression of deaf people. I am using my personal insight to investigate how and why meanings are formed about deafness and I am using the experience of deaf people to help me do this. This brings the explanations that deaf people and others have of their experience of deafness to the centre of explanations about that experience.

The focus is on questions rather than answers - whether we are asking the right

questions, in the right way, of the right people. It is about finding out what other questions we may need to ask. Harding suggests that, when thinking about scientific enterprise and enquiry,

> *"the feminist challenges reveal that the questions that are asked - and, even more significantly, those that are not asked - are at least as determinative of the adequacy of out total picture as are any answers that we can discover."* (Harding, 1987)

This process of questioning arises directly from the complexity and contradictions in people's accounts and in their experiences. This poses a challenge to the certainties we hold and asks us to release them. The study is not asking, "What do deaf people want and need?" but rather, "Why don't we know?"

The acknowledgement of tensions

> *"There is no universal conglomerate of the oppressed. Free people may be alike everywhere in their freedom but the oppressed inhabit each their own particular hell. The present orthodoxies of deliverance are futile to the extent that they fail to recognise this."*
> (Chinua Achebe, *'Anthills of the Savannah'*)

This extract, from Chinua Achebe's novel about the Nigerian revolution prior to the Biafran Civil War, identifies one of the key tensions, that between notions of difference and notions of similarity and commonality. I am interested in this study in finding out how different people understand the experience of deafness and what this can tell us about the meanings we construct. I am attempting to do this in a context of human experience and one which acknowledges inequalities of power in relationships between people because of their gender, class, race or culture, or because of the status they are accorded as dependent, passive or helpless.

As part of my investigation, I have reflected on my own experience and the similarities or commonalities between mine and that of participants in the study. For

example, one of the Deaf participants in the study describes going to boarding school - a residential school for deaf children - at the age of eleven, where sign language was suppressed by both teachers and pupils. She talks of the pain this caused her because of being taken from her Deaf family, her language and a life where she felt secure and valued as a Deaf person. On the face of it I have a similar experience, of going to boarding school - a public school - at the age of nine and experiencing the pain of being taken away from a life where I felt secure and valued. These are not common experiences between us. We are located in different classes, cultures and genders but the similarities in our experiences mean that I can understand her experience as a human one, instead of being separated from it by her deafness and my hearing.

If the research were to emphasise difference at the expense of similarity, it may well have set up an investigation that continued to treat deaf people as a separate group, whose experience is only defined in terms of deafness. One of the consequences of this may be that deaf people become disconnected from the rest of us - and from our equal human rights.

Separation is a major parameter in many participants' accounts, as are the numerous ways in which their experience is disconnected from that of people who hear and the restrictions that are placed on their ability and opportunities to make connections with each other and share. This denial of similarity and commonality seems to be a key feature of deaf people's oppression.

On the other hard, over-emphasis on similarity risks denying the different nature of that oppression. It may discount the different nature of deafened and Deaf experience, and in the use of language ('hearing impairment', 'partially hearing') or in service structures, seek to deny deafness altogether. Many participants, both

deafened and Deaf, describe their great difficulty in finding out why they are deaf, or even when they became deaf. Many interventions seek to reduce the audiological differences between people who hear and people who do not hear, but only by focusing on change in those who do *not* hear. This means that they do not address institutional and structural barriers to deaf people's opportunities to exercise choice and assert their identity, nor the imbalances of power that such restrictions create.

This denial of difference is an equally important feature of people's oppression.

A second tension arises from the way that the research process creates uncertainty. As I have mentioned, one of the consequences of dealing with issues about methodology at two levels is that I deny myself the reassurance of an accepted methodological framework. The unity I have set up between philosophy, rationale and method validates the process and the information given by participants. What it does not do, however, is remove the constant state of uncertainty into which I place myself and my work. This state has continued throughout the application of the method, the analysis and the writing of this report, provoking challenge and providing new analysis and understanding - and is *unresolvable* because the rationale seeks to promote uncertainty, not resolution.

Also, by using my own experience as a guide to understanding how deaf people are oppressed, I put myself in a position where I challenge my adopted certainties. These are certainties I have gathered to myself through my socialisation and education as a member of the dominant group in our society. They have offered me an, albeit partial, explanation of my being and the nature of my relationships with others.

An example of this is the experience of loneliness. One of the features mentioned most often by both Deaf and deafened people is about being alone, being

'the only one'. People talk with great honesty about their sense of loneliness and the isolation that has caused it. This is an experience we all have at some time in our lives and I have been reminded of my own while listening to people, analysing their accounts and writing this commentary. This has revealed insights into my own loneliness and especially about the fear of isolation that I have. Using this experience I can understand, partly, deaf people's fear but, more fully, I can understand the fear of hearing people of the isolation that deafness represents.

This challenge also needs to be continual, to reveal the 'fault lines' that provide new insights for investigation. However, the sense of uncertainty - and isolation - that this induces is, at times, difficult to sustain. I may seek certainty in established perspectives or ways of doing things. One needs to be comfortable with one's uncertainty, to be able to continue to say "I don't know", even in those circumstances when others are saying, "Well, you should".

A third tension exists between the need to find out about mechanisms and meanings and the public requirement for answers and explanatory framework. This is an issue considered in grounded theory (Glaser and Strauss, 1967) and in exchanges about the value of ethnography (Hammersley, 1990; Stanley, 1990).

To some extent this is outside of my control, as others will always have expectations of results that are beyond those intended or actually produced by any piece of work. However, one of my expectations was that I validate my work by making the information and issues contained in people's accounts accessible to others and to add to knowledge. This is especially important in an area of work where the actual level of knowledge is very low - and where the oft-repeated need for answers is a reflection of this. This manufactured value is not easily measured; people are

likely to make use of information in personal, professional or political ways in different circumstances and over time.

Significant Sources

It is clear from the experience of people participating in this study that a small number of particular sources, usually people but occasionally books or ideas, have a powerful influence in people's lives. This seems to be connected with the notion of the Third Party and the relationship between deaf people, hearing people and those who mediate contact between them.

What is especially interesting is the way in which a small number of significant sources influence the ideas and activities of professionals who work with deaf people in the personal social services - who are often placed in the role of third party.

Both these features seem to relate to the restrictions placed both on deaf people's and professionals' access to a wide range of contacts and connections. This in turn denies access to a broader set of analyses and discourses that can generate new and empowering understandings of deafness and people's experience of it.

Serendipity and fate

One of the positive consequences of a reflective attitude in the research process is that it allows for serendipity, the occurrence of the lucky chance. This arises from setting up a way of enquiry which is open enough to allow the unexpected to happen and for the investigator to be able to take advantage of it. This is most likely to happen in a form of enquiry that is permissive and which attempts to deconstruct existing forms. It represents a "fault-line", as described by Sandra Harding, which

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can reveal new sources and new meanings.

Luck, and particularly fate, seem to be important factors in the experience of participants. Many talk of the accidental discovery of information that has helped them, or a chance

meeting that has set them off in a particular direction. Interestingly, a number of social workers with deaf people described how their entry into this area of work occurred through chance. Fate seems to be crucially connected to experiences of dependence and powerlessness, often reflecting people's sense of separation and helplessness, which perhaps derives from the disconnection of deaf people's experience from our own.

Serendipity and fate have been equally apparent in the research process. There have been times when I have felt like an 'accidental researcher', blundering from one discovery to another in almost total darkness! At other times, though, a chance meeting or a fortuitous discovery in the library has created illumination and allowed me to take advantage of the insight revealed.

The acknowledgement of context

This study is attempting to place people's experience of deafness, and different understandings of it, into a broader social, political and cultural context. This is because the present context seems too limited to address the concerns, questions and experiences of deaf people or their aspirations to social justice and equality. It is also because deaf people themselves are starting to challenge the restrictions that this narrow context places on them.

How is this challenge dealt with, in the practice of social welfare, in the

development of social policy, and in the pursuit of knowledge in research? Saifullah Khan (1987), looking at cultural change in immigrant minority ethnic communities, points out that, as options for a minority increase from a previous position of limited economic and social options that create group cohesion and belonging, then this cohesion is threatened and change, which is resisted, becomes endemic to the social and cultural structure. Whose change is this and how is it enacted?

If we transpose this analysis into the social environments of deaf people and onto the interactions they have with each other and others, we can begin to see how important it is to reveal the nature of the context within which understandings occur and which construct the meanings of people's experience. A model, or understanding, of deafness that emphasises dependence and incapacity may lead to service structures where change is managed by others, mainly professionals who are part of the static and limited institutions of welfare. This will mean that people's opportunities for enacting change are limited - as are professionals' options for reacting to it. This model may also be decontextualised from broader political and social frameworks. This may occur either by our over-emphasis on a bio-medical, individualist perspective which is seen as the 'norm' or, more importantly in this context, because the assumptions, attitudes and ideas that underpin the model are not acknowledged.

If this happens, deaf people are likely to be denied the power to challenge, mainly because they are unable to find out what it is that they are challenging.

How do we reveal this broader context, and place deaf people's experiences within it? One of the principal routes into this is by my identification of the structural features of my experience - my gender, my class, my race - and how these may affect the meanings I create. But it is also achieved by making the process of discovery

itself - the methodology and the method of enquiry - explicit, setting out the sources for illumination, guidance and ideas and how these formed the methodological frame-work.

Describing this process highlights four key issues which arise from sets of questions put during the course of its development. These questions are roughly chronological, but not absolutely so, as I have moved backwards and forwards across different sources, at different times, to address different issues. This flexibility is an important feature of the way in which the methodology has been developed.

The first issue concerns the need for analysis of the research process and of making it explicit. It centres on questions of what a methodology is and on what kind of methodology I need to adopt to enable me to look at the issues I want to investigate. Bulmer (1982) describes methodology as the means by which the structure of the social sciences, combining theory and empirical evidence, is "maintained and kept standing solid and upright." This implies that one of the main purposes of methodology is to validate and authenticate the process of social research. For me, this is extended to cover the validation of the research topic and give form and meaning to the questions being posed. It also has the purpose of authenticating the source of information about the topic - people's accounts of their experience.

Making this process explicit enables people to engage with the research topic and with the range of issues and themes that are revealed in its investigation. Burgess (1982) acknowledges the importance of analytical discussion of the methods of social research, and Spradley (1979), in describing issues about ethnography, highlights the importance of matching the method chosen to the subject matter under investigation. My purpose was to find out how different people understand the experience of deaf-

ness, and the straightforward way of doing this was to ask them.

This leads to the second issue, which concerns language. Hammersley and Atkinson (1983) emphasise the central importance of language in ethnographic research and especially of what questions to ask and how to ask them. This, though, is only part of the issue. It is also a question of who uses language, why, and how it is used. Feminist critical analysis of language is crucial to understanding these issues and provides a key to ways of using people's own accounts of their experience to reveal new meanings. Spender (1980) highlights the use of language to classify, order and manipulate reality, and asks what terms are used in this process to describe norms or classifiers. In relation to men and women, this is especially important in describing relationships between the two groups. Padden and Humphreys (1987) describe the different centre that exists for Deaf people and how the use of language reflects this.

Gilligan (1982) elaborates on the different voices that people use to talk about themselves, their experiences and the connections they make and the way that language reveals the different themes that men and women pursue. She also highlights a crucial element in listening to people's voices and bringing out their accounts:

> *"The method of interviewing was to follow the language and the logic of the person's thought, with the interviewer asking further questions in order to clarify the meaning of a particular response."*

This acknowledgement of the different ways in which people describe their experiences is important. It gives people permission to express themselves in the language they choose and it values what they say. It is an important element in the third issue, which is about the meaning of people's accounts. This centres on questions about what the experience of other groups might tell us about that of deaf people.

Cornwell (1988), in a study of working class people's perceptions of health,

distinguishes between public and private accounts of health. This points up the relationships between the account-giver and the account-receiver, and that people hold accounts which they only share with certain people - and, more crucially, feel that they are not allowed to share with certain others. Public accounts may be constructed out of the reality that people perceive and which is imposed on them. Saifullah-Khan (1987) highlights this in relation to minority ethnic groups:

> *"Members of ethnic minorities are creating meaning to adjust to the reality in which they find themselves."*

This connects also to the ways in which an imposed language forces people to adopt a changed reality, as Chinua Achebe describes:

> *"Is it right that a man should abandon his mother tongue for someone else's? It looks like a dreadful betrayal and produces a guilty feeling. But for me there is no other choice. I have been given the language and I intend to use it".* (Achebe, 1975)

Some people of course, and especially men, have more control over the circumstances in which they can assert their language use - and their identity - than others. Gilligan (1982) highlights this and emphasises the importance of understanding the existence of public and private accounts and the power of acknowledgement:

> *"The difficulty women experience in finding or speaking publicly in their own voices emerges repeatedly in the form of qualification and self-doubt, but also in intimations of a divided judgement, a public assessment and private assessment which are fundamentally at odds".*

Rubin (1972), in her study of working class family life in America, talks of the importance of understanding the meanings that people attribute to their lives and behaviour and not just to understanding the behaviour itself. My Deaf colleague found significant resonances between the experiences of the white working-class women in Rubin's study and her own as a white, Deaf woman and provided an important source for understanding commonalities between different experiences and how these could

be incorporated into the research methodology.

This leads to the fourth issue, which is about making the perspectives and purposes of research overt. Harding (1987) provides the crucial framework for this. Her analysis of the influence of feminism on methodology focuses on a number of features that characterise a feminist approach, which crystallised for me the central importance of language and the acknowledgement of people's experience:

- the use of women's experience to develop new empirical and theoretical issues;
- that the purpose of research is for women;
- that locating the person making the enquiry, and his or her perspectives and purposes, in the same place as the people participating in it, reveals new subject matter.

My analysis of research methodologies in a selection of studies of the experience of deaf people seemed to show that current ways of understanding deafness are based on methodologies that, on the whole, do not address these issues (see Appendix 1). The experience of deaf people is often marginalised, different groups of deaf people may be denied the use of their own language in research, and knowledge and information about deafness is still largely obtained from exclusive and unelaborated understandings. These tend to be characterised by an ethos which separates the experience of deaf people from that of others and ourselves and this restricts opportunities to give meaning to people's experiences.

Others' analysis, of making the research process explicit, of language and power, of the meaning of personal accounts and of making perspectives and purposes overt, suggest new ways of developing methodologies and revealing new meanings and subjects for study.

So, this study has a methodological framework whose principal features are;

- a qualitative base, which seeks to address the imbalance inherent in traditional understandings of deafness, and which is informed by feminist perspectives and analysis;
- the use of two languages, British Sign Language and Spoken and Written English, in the collection, recording, analysis and presentation of information;
- the active use of researchers' perspectives and experience in obtaining and understanding information from participants;
- conducting interviews in such a way as to enable people to explain their experience in the way they want to;
- the incorporation of deaf perspectives into the design and operation of the research, whose principal language of description is English;
- the incorporation of the research philosophy, to promote principles of social justice (inclusion, connection and respect) and equality in the unity between what is being investigated, why it is being done and how it is going to happen.

CHAPTER 3

THE METHOD

How did this framework translate into practice during the collection of information and its analysis? This chapter describes the method of doing the research and is set out in the following format:

Overview

- The Interview Structure
- The Group of Participants
- The Access Process - engaging participants
- The Contact Process - finding participants
  - Key informants
  - Direct contact
  - Rolling contact
  - Groups and agencies
  - Serendipity.
- Testing Structures
  - the Pilot Study
  - the Main Study
- The Reflective Process
- The Analysis

This format allows me to describes the whole process of the research method, the influence of reflectivity and the crucial importance of the developing relationship between myself and my Deaf research colleague to the process of reflection.

Overview - process and discovery

This format suggests pattern, logical progression and regulation. Indeed, it seems traditional to describe the method of doing the fieldwork and analysing the information gathered by setting out the processes involved in gathering information - what means were selected, why, how this was done, with what groups of people, how these were selected - and presenting them in a way that suggests they developed in an orderly, planned and controlled way. Mine did not. I sought to test out different processes and in doing this found out that the method worked far better than I had anticipated and clarified some important issues about methodology and ways of creating meanings about deafness. This was my intention, so I will describe the method in a way that tries to highlight these discoveries and how they have occurred, as well as explaining what I did.

I have used extracts from my working diary to illustrate some of the features of this process of discovery and, particularly, the influence of the reflective element in the research. I feel this gives a flavour of the uncertainty, excitement, anxiety, questioning and loosening that is created by this reflective approach. Acknowledging my feelings helps me to be more open to the emotional impact and meaning of people's experiences - and can be overwhelming. The questioning and loosening help to liberate me from some of my received ideas and assumptions about deafness - and can leave me floundering. These tensions reveal important issues about methodology, about what people experience and how to understand their accounts of deafness.

"Something is missing. It could be my sense of passion, urgency.

If I am going to make this work, I will have to put in some hard graft now, and organise my time better.

My sense of floundering now is the same as my sense of floundering

when I was in practice. I feel angry and resentful that I have to shoulder all the work and responsibility - on my own. I have no reference points for my struggle to understand save my own value system. And when the passion leaves, which it is bound to from time to time, I have little that I can see that I can fall back on."

The Interview Structure - listening to people

"How to deal with the trust relationship with participants, and not to step over the line of what we offer. This is in fine balance, and it is an equal relationship... The trust develops from the equality of reciprocity."

The value system that underpins the research is contained in the principles of the research rationale and central to these are principles of equality and respect for others. The focus of the research is on understanding deafness through the experience of people most intimately connected with it - people who are deaf. At the heart of this approach is a belief in the validity of people's accounts of their experience and the choice of structure to elicit these accounts is guided by this.

This suggested an interview structure that was semi-structured rather than open-ended. A completely open-ended structure would deny control to participants and the only equality in it would probably have been the fact that neither they nor I would have been aware of the nature of information being sought or used.

The interviews were structured around five stated general topics of discussion - experiences of deafness, information, significant happenings, technology and services (Appendix 2). These topics were made available to participants prior to interview, to give them an idea of the framework and content of the interviews. The topics fulfilled two functions:

1) To give participants a structure for their accounts of their experience;

2) To find out people's general attitudes towards these topics.

It was not my intention to obtain quantitative information about services and technology, for example, but to use them as jumping off points for discussion and explanation.

What became apparent during the course of the interviews and in the analysis, was that the content and quality of people's responses to these topics touched on much broader and deeper issues than the specific topics themselves and it is these larger issues with which I am primarily concerned.

> *"For the first time today I had a real sense of the way that our understanding of deafness can and is developing from the explanations people are offering. This seems an important breakthrough."*

I also wished to accord people the opportunity to talk about their experiences in the way they wished to, and this was made clear on the topic sheet and at the interview. This was one of the structures being tested. In addition, people were given the choice of which language they wished to use to present their accounts, Spoken English or British Sign Language, and knew that their interview would be with a native user of that language who would share a social or cultural experience with them. This was the primary reason for the appointment of a Deaf interviewer, but her role developed into a more crucial one as the research progressed.

> *"I have been anxious about sharing the day-to-day work of the project with someone else, and about actually getting started on the project. Sheila's arrival has achieved two things; it has stimulated my interest and allowed me to explain the project over again and clarify my thinking, and to see how it is constantly developing, rather than being static. Secondly, she has enabled me to open up again; I was becoming closed down".*

The role of the interviews, again in accordance with principles of respect for participants and their accounts, was to help them to give their accounts and to ask questions that helped people explain what they wanted to say, rather than to provide particular

answers to specific questions. This demands considerable concentration and was one of the main reasons for deciding to record the interviews in total using audio and video tape. This freed the interviewers to give all their attention to participants and what they wanted to say.

This created some difficulties in transcription and analysis, largely because of the large amount and complexity of information obtained. However, the advice of Deaf consultants in particular was that we really had no choice but to use video for Deaf people's accounts, as BSL has no written form and notetaking or transcription at the time would only provide an English version of a signed account. This issue of language is considered more fully on the analysis section.

The topics in the framework were chosen as ones that were most likely to connect with people's actual experiences in the context of this study. As the research originated in my professional practice and sought to address some issues about service provision and helping, issues about technology and services seemed relevant.

Asking people to think about early experiences of deafness was seen as a way in to issues about discovery and resolution of identity and language, and information connected to ideas I was starting to develop about significant sources. The one topic that people had the most difficulty in addressing directly was about significant happenings or events. Asked about these boldly, people are often at a loss as significant events always have a context, and it became clear that people *did* speak of their significant events when they were able to describe them from the context of their own accounts.

People did not always cover the issues in the order given, nor did the interviewers insist on this. They allowed people to range across the topics in their own

way. Some people made notes of what they wanted to say; interestingly, they often did not refer to them when giving their accounts. Some others deliberately did *not* read the topic sheet, wanting to react spontaneously in the interview. Many of these people were in the professional group.

A range of comments about the topics, questions and structure of the interviews, from people in all groups, give an indication of the success of this format and are discussed more fully in the section on Testing structures.

The Group of Participants

In order to collect information to reveal meanings using this interview structure, I wanted to be able to talk with as wide a range of people about their experience of deafness as was possible within the limits of time and resources and which accorded with the principles of the methodology and the intention of the study.

My purpose was to identify the parameters of a possible framework of explanation, which derived from people's accounts of their experience. It was not to gather quantitative data about predetermined parameters; this could be done in subsequent research programmes once parameters had been identified. Therefore, it did not seem appropriate to select participants by random sampling and place them into identified subgroups around race, gender, class, culture, language and age as these might well predetermine the nature of the information people were able to give us and the ways we understood it. This purpose was guided by the principles in the rationale that emphasised the importance of *all* accounts and of creating opportunities for people to give their accounts in the language of their choice and the ways they wanted to.

So, the composition of the group of participants was determined by identifying

different groups of people in terms of their language use, their cultural experience and their social outlook; by locating participants in different geographical areas, with a mix of rural and urban environments, services provided directly by Social Services Departments or through contracts with voluntary agencies, and geographical areas in the North, the Midlands and the South of England; and finally, by using a variety of contact method and sources of contact.

My investigation of attitude studies and other research studies about the experience of deaf people had shown me that there was often no clear distinction between groups of deaf people in these studies in terms of their use of language, their race and gender experiences, their class or their cultural and social experience. One of the features of the study was how the methodology might address these issues.

This led me to distinguish between two groups of people who were deaf, in terms of their use of different languages and their different social and cultural outlooks. Firstly, there was the group of people who use sign language as a first language, who have a cultural experience as Deaf people and whose social interactions were as people who had never heard (the Deaf group). Secondly, there was the group of people who used spoken English as a first language who, by and large, had a cultural experience as hearing people and whose social interactions were as people who had previously heard (the deafened group).

My professional experience suggested to me that there was often a gap between what professionals might know about deafness and how deaf people experience it. This indicated the need for the third group, which comprised professionals in the personal social services who either provided services directly, or had responsibilities for managing or planning them (the professional group). The people in this group

were mainly hearing but there were some Deaf professionals as well.

The inclusion of service managers and planners was partly guided by the fact that there were unlikely to be enough social workers or other direct service providers for this group but also because my professional experience again suggested that decisions about the form and content of services were often not in the hands of providers and were influenced by other factors and people. It seemed important to find out about the experience that these people might have had of deafness and how this might influence them. The relative powerlessness of social workers, incidentally, often contrasted sharply with deaf people's expectations of the power and influence of direct service providers and has a direct bearing on issues about the Third party.

A range of geographical areas for the fieldwork was identified in order to help in the process of revealing a range of experiences. Four areas were approached: one in the North of England where services were provided in an urban / rural area by a local voluntary agency under a contract with the Social Services Department; the second in the Midlands, where services were provided in a predominantly rural area, with several small towns, directly by the Social Services Department; the third in the Midlands, in an urban area, with services provided directly by the Social Services; and the fourth in the South of England, where services were provided in a rural area with several large conurbations, by a local voluntary society under contract to the Social Services.

This use of different areas created a considerable degree of flexibility in identifying a range of participants, as this extract from my work diary demonstrates:

> *"The nature of this fieldwork, or at least of doing it, is starting to change my expectations of what we can get. As time is limited, I am thinking wider and quicker, perhaps more laterally. What I thought today was that we do not have to get a perfect balance of interviews*

> *<u>in each area</u>. We should use the fact that we have chosen different areas for different experiences to concentrate on particular kinds of experience in each one. If we can interview more men in S_____, we can interview more women in another area."*

The Access Process - engaging people

In the event, three of these areas agreed to participate and one, after initially expressing interest, withdrew. The process of engaging participation has a number of interesting features, partly because of this remarkable rate of success. I will describe some of these briefly. In the first instance, the level at which contact was made ensured that the people who would participate were engaged from the start. This point of contact was with the people who directly managed practitioners. Interestingly, in the one area where contact was not made at this level, the area withdrew. People were therefore engaged from the start in a sense of ownership of the research process - something I wished to promote in all three groups - which helped people to feel that their accounts were being valued and acknowledged.

Secondly, this method of engagement focuses attention on the third party and the role of significant others in providing contact and access. The importance of these third parties in this respect varied from area to area, with some key informants providing a wide range of contacts, and others very few. It would seem that issues of empowerment are important influences here, both in terms of the empowerment of the third party and the empowerment of the individuals or communities to which they gave access.

The Contact Process - getting in touch

The study used a variety of ways to make contact with participants. This was

done for a number of reasons. Firstly, and most significantly, using a range of sources for contact would help to ensure that I had access to a number of different kinds of experiences. This was partly because of my awareness of the role of social workers or other similar single providers of services as gatekeeper and as access points to Deaf people and the Deaf community for the majority of hearing people. This is an important feature of the role of the third party and I wanted to see how this role was enacted by different key informants.

Secondly, I was aware that the contacts made through social workers and other service providers were likely to be with particular groups of people, either those who are clients or those who are actively involved in promoting the Deaf community or the perspectives of deafened people. These are important groups but so are those of people who are not clients or users of services and those who are ordinary people in their communities. The main way of trying to do this was by setting up direct contact with Deaf and deafened people, either individually or through groups and clubs and using a Deaf researcher to make some of these contacts.

Thirdly, I wanted to see what range of experiences might be revealed by a variety of methods of making contact and by trying to involve participants in this process, enabling them to make some of the decisions about whose accounts to include.

The contact process for each of the three areas is illustrated in Figures 1-3 (see Appendix 3). There are a number of important features in this process: the role of key informants; the use of group of discussions and interviews; serendipity; and the use of rolling contact.

Firstly, let me look at issues about *key informants*. In the first instance, contact

was made with a single significant source based in the agency responsible for direct provision of services. The influence of these significant sources varied from area to area: in Area 1, this person was the key source of contact to a range of people in all three groups; in Area 2, this person was only significant in contacts with the professional group; and in Area 3, the person was one of a number of key informants who provided access to a range of people in all three groups.

Each significant source was briefed in the same way (as were other key informants) to provide access for us to people with a range of different experiences who were users and non-users of services and who had regular or little contact with communities or groups. The differences between the sources in terms of their effectiveness in achieving contact was probably due to a number of factors but one of them seems to be connected with the degree of empowerment or powerlessness in relation to the different groups with which they make contact. The following extract from my diary may help to illustrate this:

> *"I have a sense in this area of information being <u>much</u> more closed, notwithstanding people's willingness to help, and wish to co-operate. The 'Ethics Form' and the reaction of the chief audiological technician (<u>very</u> guarded), and Donald's reluctance to give me reports, or any access beyond a minimal level, give a sense of guardedness, as does the fact that the Centre does <u>not</u> mention the hospital, and the hospital does not mention the Centre!"*

However, it was possible to identify and use a number of key informants and to get access to a wide range of different experiences in this way, especially in the professional and deafened groups. This did not apply nearly as much in the Deaf group, where direct contact was made by the Deaf researcher through groups, clubs or with individuals. In many respects, the Deaf researcher became the key informant and the significant source and this perhaps explains why there were many more women than

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men interviewed in this group. However, there were also more women than men interviewed in the deafened group and the key informants for this group were both women and men.

A significant feature in the success of the Deaf researcher in reaching a range of people was her skill in engaging Deaf people through *group discussions* and explanations and this method was a source for a number of professional contacts for me as well. Her ability to do this rested partly in her being able to connect with people's experiences directly and to engage with them through these. This applied to me as well, in the professional group, though not in relation to the deafened group. People in this group were far less likely to meet as a group, except for specific reasons (a lipreading class or a support group), so engagement in this group derived less from group contact and more from individual key informants.

Here, *serendipity* played a more important role. The creation of opportunities by lucky chance is an important feature in the methods adopted in the study. This meant being open-minded about the kind of experience that could be included and the structure made this more possible than one that was more definitive about the groups of people to be interviewed. In one instance I was given the wrong telephone number for a contact by a key informant and found myself talking with the mother of two deaf sons, rather than the lipreading teacher I was expecting. I decided promptly to follow this up, made an appointment and obtained an extremely important and revealing account from both mother and son.

Serendipity is enhanced by the process of *rolling contact* which was adopted to reveal additional sources of experience and to involve participants in the choice of people whose accounts were to be valued. About a dozen participants were contacted

using this method and although this is a relatively small number, it did mean that decisions about whose accounts were valid were spread over a range of people, including participants and not just the researchers and key informants. This adds to the variety of experiences that were included in the study.

In total, 111 people were interviewed. 63 were women and 48 were men. Four Black people and three Asian people were interviewed and three professionals were Deaf. Figures 1-3 (Appendix 3) give details of the composition of the group of participants for each area.

Testing Structures - empowering participants and empowered accounts

> *"At one level, I now think we have a framework to start our questioning process, but I do still feel as if it is not working. We really must start."*
>
> *"The research is in several disparate parts at the moment. It almost feels as if I have been constructing various parts separately, and am now worried that they may not fit together."*

These two extracts from my diary introduce aspects about testing issues of methodology, particularly those about empowering participants and affording them respect, and those about the structure of the interview format and how it was conducted.

First of all, a pilot study was conducted in two areas local to Bristol, which tested the interview structure and questioning process, the contact process and its ability to identify a range of different experiences, the ways of recording information and some features of analysis. Several interesting findings arose from this:

1) Our role as researchers was different from roles that we had previously adopted when listening to or questioning people. For my part, I realised the difference between listening as a social worker and listening as a researcher. This centred on differences in the exercise of power in each relationship and

on ways in which each afforded equality and respect to participants. As a social worker, I listened as someone who 'should' be helping - and helping in certain defined ways - and I was often confronted with my own powerlessness to help, or to help appropriately, in the face of others' pain and difficulty. As a researcher, I was listening and paying attention in order to acknowledge that pain and difficulty, without the expectation of its resolution. The fact of acknowledging people's accounts accorded them value and gave participants respect and a greater sense of equality.

2) The interview structure was successful in allowing people to make their own accounts and gave information relevant to the purpose of the study.

3) The choice of recording methods was valid, in that people were not put off by the tape player or video camera and that using these allowed the interviewers to concentrate on helping people put together their accounts.

4) People's childhood experiences of deafness often centred on women (grand-mothers, aunts). This focused on the issue of gender experiences and, although the study was not specifically looking at these, people's accounts suggest strongly that gender is an important issue in the creation of meanings about deafness, that men and women may well perceive deafness in different ways and that this needs to be the focus of a future study. The discovery of this issue at the pilot stage helped to bring this issue to the fore.

The testing of issues about methodology, however, continued into the main study. Using three areas helped to test out a range of different methods of making contact, as can be seen in the contact trees in Figures 1-3. These enabled us to make contact with a variety of people of different ages, experiences, gender, class, race and culture.

Furthermore, the choice about who to contact was spread over a number of different sources: another way to create a variety of experiences.

The issue about methodology that was of major interest, though, centred on the potential of the interview structure to enable participants to give their own accounts and to address the

questions and issues that people felt were important. We asked people about this specifically and their comments encompass a number of issues.

First of all, they address the focus of questions and the range of topics in the interview. People made a number of comments when asked whether the questions were the right ones to ask, or if they were important questions to ask. These two questions elicited different kinds of responses from participants. They tended to consider 'right' as being 'right' for the research, but to see 'important' as being 'important' to them.

> *"That depends on what you are trying to write. You obviously perceive you are asking the right kind of questions for the kind of angle you are trying to write about. You've got to know where you are going to know whether what you are doing is going to get you there. But, on the assumption that you are going to try and write about how it is for them - 'How was it for you, darling ?' - then, yes, I think its necessary to ask those sorts of questions."* Hearing woman, professional, age 35.

> *"What, the questions you are asking me? You've got to start somewhere. I accepted that you had to choose a direction, and I accepted that deafness was the direction".* Hearing woman, professional, age 52.

The use of the two different words seems to indicate a change in involvement and responsibility.

> *"Yes I think so. They seem to delve into a deeper understanding, yes. Absolutely."* Deafened woman, age 60.

> *"You have been very good, really. You have asked everything that is really important."* Deafened woman, age 70.

"I think they are critical ones to ask, and I have personally been very stimulated by the questions you have asked, and it has been a delight to have the opportunity to think in a single minded way about issues related to a particular client group. We should create more opportunities to do that, I think that is the message I have gained from this afternoon."
Hearing man, professional, age 45.

This difference in influence and involvement is also apparent in Deaf people's responses to a question about how they would react to a hearing interviewer.

"Well, a hearing person might have qualifications and certificates in interviewing but I still wouldn't feel right, because it wouldn't be my preference ... it would probably be over my head, their signs would be different ... but if their parents were Deaf, and the person signed well, yes, that would be ok ..."
Deaf man, age 52.

Being understood, in terms of both language and culture, were clearly key features for Deaf people in feeling comfortable in the interview structure.

"Yes ... if I was able to understand the hearing researcher, I would feel comfortable. If I didn't, I wouldn't! If the hearing person used sign language clearly and had good lip movements, then that would be ok".
Deaf man, age 25.

Interestingly, this feature of being understood applied to members of the professional group as well, as this comment from a former welfare officer illustrates.

"Oh yes, very comfortable. One feels that one might be ridiculed to some extent, but one can only say what one has experienced".
Hearing man, (former) professional, age 66

There were a number of comments about the interview format and the validity of using interviews rather than questionnaires for this sort of information. Again, this seems to be related to the extent to which people feel in control of giving or not giving information.

"Questionnaires never quite ask, or never quite give people the opportunity, I think, to say what they want to say, no matter how comprehensive you try to make it. If you make it too comprehensive, it is too complicated for people to pick their way through. Yes, an interview is the ideal way, especially for this sort of thing, I think. If you are asking people about a level of service, or something, ticking boxes is

fine. But you can only really get an in-depth view of what people think and feel this way". Deafened man, age 65.

The format also seems to have given people the chance to retain their sense of who they are - which is, after all, a central focus for the research.

"Yes I am grateful to you for that [giving a chance to explain experience in the way she wanted to], because you did not narrow it down to a system. Yes, I feel that whatever I have told you, no matter how it has come out, if you played the tape back to me, I would recognise it as me. I wouldn't feel cheated, feel that I was an artefact of your interrogation. So, yes, I am well satisfied with that".
Hearing woman, professional, age 52.

This sense of acknowledgement is one of the key positive features in the interview structure and seems to be a significant contributory factor to the range, depth and richness of people's accounts. It is an acknowledgement of both experience and self and seems to validate people's sense of who they are, which people are clearly not used to.

"You mean, people will listen to me, what I have been saying?"
Black deafened woman, age 26.

"I can't help but feel that I have just been talking about myself, and you wonder if you are wasting everybody's time". Deafened woman, age 63.

"Oh yes, definitely. There's lots of different areas that I've covered in a very general way because I've said things, and I thought of others as I said it, and I think it's very interesting, that."
Deaf man, professional, age 29.

A key element in creating this depth and richness is people's willingness and ability to be reflective about their experiences, often for the first time.

"Yes, because they haven't been 'yes or no' questions. They have been very open-ended, and I could sort of play it the way I wanted to, really. You just sat there, listening, and went along with what I have said. Yes, I think so, you have allowed me to get off my chest, if you like, the things I wanted to. Yes." Deafened man, age 60.

"Very much, yes. I appreciate the way you have put the questions, because it has not only made me think about the issues around the facts,

but also taking them a bit farther, and I think that's important. Otherwise you are just dwelling on a fact or two. And it does help me to express, particularly my childhood experiences, because I haven't really had an opportunity to do that or to speak about the significance of those very much before. So, thank <u>you</u>, too." Deafened woman, age 38.

"What you have actually got, is a gut response. If the questions had been written down, you would have got a much more articulate and concise and, yes, brevity would have ruled the day, and it would be 'talking heads' stuff. Because of the way you asked the questions, and I knew I was being led that way, I was quite secure and safe. So, you have to be congratulated about that, because I need to feel secure to talk, and I have come right out of role. What I have done, is engage very much in the lower realms of my anatomy, and I think that is interesting. I am still in that particular mode, so I can't answer your question yes or no. But you asked me a minute ago about the interviewing. I think that the success of the style has been that you didn't ask me in advance, you didn't give me sight of the questions, because I think the thing for me is, so linked are they to the unconscious - that is, the motivating thing, the forces, the very important issues about why I do what I do. Because you didn't ask me what the ethics and values are that underpin my work. What you actually asked me was my first impression of a deaf person. OK, now if you had asked me that on a piece of paper, I would have immediately assumed you were talking about our clients, because it is an official piece of paper, so I get into the role as manager, I respond as a social worker, so I become client-centred, client-oriented. Because you asked me, and we started to interact at that level, and it was very relaxed, I told you about my grandmother. I would not have told you that if you had asked me on a piece of paper. So, why did I, as a manager, need to tell you about my grandmother ?" Hearing man, professional, age 42.

The Reflective Process

People's ability to reflect on different aspects of their experiences and to put together a coherent account on their terms derived in part from the structure of the interviews and the way of interviewing, but also from the reflective element built in to the research methodology. This reflectivity, as I have discussed previously, influenced the development of a number of features in the study. I can illustrate this using extracts from my research diary that reveal issues about fear, the third party,

and the nature of power and control exercised in third party relationships. These derive from my reflection on my own feelings, and on the processes in the study.

> *"Just prior to my interview this afternoon, I felt a sense of tensing up/, of becoming angry, and this was because of not having confidence in my ability to communicate with _____. I was frightened of her, and of failing to communicate."*

This association of fear and lack of communication helped to reveal connections between experiences of isolation and being alone and how hearing people might react to the isolating effects of deafness. This developed further when reflecting on the defensiveness of some professionals and their reluctance to engage with the research.

> *"I have the feeling today that much of the way services are created and provided revolves around particular personal relationships, and that the emphasis on personalities within this work highlights this. Part of my intervention is to expose these tensions, and that this is part of the fear of the people in the interviews".*

The importance of reflectivity is being able to get in touch with my human experiences and reactions and use these to develop an understanding of different experiences, of which I have no first-hand knowledge. Working with my Deaf colleague was probably most influential in opening this up for me, as these two extracts show;

> *"Sheila's arrival has achieved two things; it has stimulated my interest and allowed me to explain the project over again, and clarify my thinking, and to see how it is constantly developing, rather than being static. Secondly, she has enabled me to open up again; I was becoming closed down".*

> *"We have been developing well and fast in being able to support each other. I still feel I do not support her enough, but that, I think, is in ways that I am <u>unable</u> to _____ that is, in the <u>sharing</u> of the experience of deafness. My own humanity is just as important and I should share it, and show it, without fear."*

Keeping in touch with my own reactions and maintaining a positively reflective attitude clearly translates into the interview process and is enabling for participants. It can, though, be difficult to maintain over time and this was especially the case in the

analysis stage.

The Analysis - a framework of understanding

People's accounts were analysed by a process of content analysis. This identified issues in accounts (approximately 2,000 to 3,000 in each account), which were then organised into parameters (approximately 25 to 30 in each account). The starting point for determining parameters for each account was the researcher's judgement about what were the most important group of issues for each individual. Figures 4-6 show examples of this process from each of the three groups of participants. For many people, the focus was on identity and self; for some, it was on culture or family; for others on community and belonging. It became clear that the parameters were broadly similar in most accounts and that this covered all three groups. This is probably not surprising, given the common topic structure used for interviews in all three groups and the consistency in conducting the interviews, but the analysis does reveal some quite startling commonalities in the experiences of people in all three groups, suggesting at one level, for example, that language oppression was as much an issue for deafened people as for Deaf people and at another the almost symbiotic relationship between practitioners and deaf people, and Deaf people in particular.

These parameters form the framework for an explanation of deafness that derives from people's accounts. They create what Becker (1966) calls a mosaic:

> *"Each piece added to a mosaic adds a little to our understanding of the total picture. When many pieces have been placed we can see, more of less clearly, the objects and the people in the picture and their relation to one another. Different pieces contribute different things to our understanding; some are useful because of their colour, others because they make clear the outline of an object."*

The picture they form originates in our interpretation of the issues people raise in their accounts, but this interpretation attempts to remain as true to people's experiences as is possible, through giving people a choice of language use and conducting interviews in such a way as to encourage people to give their accounts in their own way. My commentary on these issues uses people's accounts of their experiences as the references for the points that it makes and arises from the framework of explanation that these parameters produce (see Figure 1).

FIGURE 1: PARAMETERS

Chapter 5	**SELF** Search for self Personal Struggle for self Own Knowledge Self-realisation	**IDENTITY** Becoming human Loss of identity Discovering identity Being deaf Becoming deaf	**CHALLENGE** Struggle Confronting Self-assertion Change Anger Fight Control Power Ownership Choice
Chapter 6	**VOICES AND LANGUAGES** Culture Race Gender Class Social experience Age Language Family	**RESTRICTION** Restriction of Ambition Not allowed Limitation Exclusion Passive Lack of Control Service structure Technology	
Chapter 7	**DENIAL** Pretending Hidden Private Unacknowledged Avoiding Witholding Not Knowing	**SEPARATION** Aloneness Only one Own Isolation Disengagement Disassociation Independence	**POWERLESSNESS** Loss Fear Embarrassment Ignorance Passive dependence

Chapter 8

ACKNOWLEDGEMENT
Admission Listening Open
Naming Knowing Public
Realisation Letting go
Conscious Understanding
Showing Availability
Explanation

COMMONALITY
Connection
Inclusion Collective
Access Human contact
Sharing Belonging
Work Shared interests
Company Group
Community
Corporate services
Active dependence

HELP
Helpers Care
Watching
Helping Support
Being There

THIRD PARTY
Bridge Source
Best friend Protector
Guide
Supporter Informant

MORAL POWER
Rights Obligations Blame
Professional integrity
Equality Freedom

There are a number of interesting features in the analysis process. Firstly, there is an issues about the language of analysis or, more specifically, to which language the analysis is applied. For deafened people's accounts and those of hearing professionals, interviews were transcribed into written English and the analysis made on these written transcripts. We attempted to do this with Deaf people's accounts, transcribing sign language on video into a written English form, but found that this seemed to alter the meaning of people's accounts. We decided to try and analyses directly from the video, allowing the Deaf researcher to interact with the issues in people's accounts in their, and her, first language, using English notations that best corresponded to these signed issues. This procedure was very time-consuming but did mean that Deaf people's accounts retained their signed meaning for longer, until they were translated into the language of the research study.

Secondly, the analysis was interactive because the research takes an active part in revealing people's issues and ordering them into parameters. The process of analysis was manual, writing issues onto cards and sorting them into topic area, then parameters. Again, this is time-consuming but does allow a flexibility in the identification of topics and parameters that a software programme, such as 'The Ethnograph', might not. The purpose of the analysis was to see what parameters might be identified from issues and information contained in people's accounts, not from ones that were predetermined by myself or in a computer program.

Thirdly, there is an important issue about dealing with the emotional impact of people's accounts. This extract from my research dairy highlights some of the features in this:

> *"Listening to people's stories opens me up to their pain, and reminds me of my own. I feel their hurt, and my own. It is very demanding,*

and leaves me quite vulnerable".

Collecting people's accounts and reading and re-reading them as part of the analysis, creates an accumulation of issues, ideas and emotions in the researcher. These are not mine, yet by adopting an interactive and reflective approach, I bring them into contact with my own. This can affect the interpretation I put on people's experiences and needs careful monitoring, by myself and by reference to others, to ensure that this accords with participants' experience and does not distort it. An example of this is my treatment of the issue of separation in the commentary. A number of people, especially Deaf people, described experiences of separation associated with going away to boarding schools. These experiences were characterised by feelings of loss and pain, but also of discovery and acknowledgement. My experience of going away to boarding school predominantly created for me feelings of loss and pain. Reading about others' experiences exposed these feelings for me and, incidentally, helped me to resolve some of them. This exposure created a tension between two opposing effects. On the one hand, it helped me to understand some of the issues around separation, loss, discovery and acknowledgement, but on the other required me to revisit sites of my old pain. On balance, I feel this exposure has been worthwhile but at some cost to myself.

The success of the interview structure and process of analysis is measured predominantly in the rich, complex, honest, revealing depth of people's accounts and the successful application of the principles of the research can be seen in people's willingness to present their accounts in this way.

CHAPTER 4

INTRODUCTION

The form of the commentary

In the following chapters I describe the issues which people talk about in their accounts. These accounts are rich and complex and I have sought a way of revealing this and of showing how it can be elaborated into a 'framework for understanding' which can open up new meanings about the experience of deafness. I have endeavoured to do this by using a commentary, a form of continuous comment and noting, which is my interpretation of what people have said and which allows me to range over the diversity of issues contained in people's accounts. This commentary is built around extracts from these accounts and follows the mosaic created by the parameters identified in the analysis.

This form of description allows me to address some key issues about methodology and to begin to formulate an explanatory framework that fulfils the requirements of the research philosophy and rationale and addresses the research questions. It helps to establish the validity of personal accounts as evidence with which to address the research questions and from which to develop this framework. It does this in a number of ways:

- by acknowledging and respecting the integrity of the accounts and of each of the people who have given them;
- by showing how the parameters arise and how people's own explanations of their experience can form the basis for ours;
- by demonstrating the values of a different way of revealing meanings that is

inclusive, utilitarian and transformational.

There are three features of the commentary that merit some elaboration to help clarify those issues.

A common framework

Firstly, the commentary incorporates extracts from all three groups of participants into a *common* framework. While acknowledging differences between them, it does not deal with each group separately. There are several reasons for this.

The analysis revealed a remarkable degree of similarity between issues raised by people in each of the three groups. This is clearly related to the common set of topics presented to all participants, around which interviews were conducted but it may also reflect the fact that there are common *human* experiences between Deaf and deafened people, and professionals who are hearing. Acknowledging these common experiences may help us to understand the almost symbolic relationship between deaf people - and especially Deaf people - and the mainly hearing professionals who work with them.

The analysis of meanings proposed by feminist methodology in particular, suggests that forms of explanation that do not acknowledge both difference and commonality will be likely to be partial and obscurantist.

The research intended to seek common framework for understanding, rather than to focus only on difference in order to try and understand some of the reasons why this focus has tended to predominate meanings of deafness.

This feature of the commentary, then, focuses on the importance of emphasising both difference and commonality. The research rationale and the struc-

ture of the information collection attempted to create an equality between different experiences, in order to uncover a variety of meanings and ways of explaining the experience of deafness and to give these equal value. This is done by acknowledging *different centres* and by highlighting the *unitary nature* of experiences of deafness and hearing, placing them on a single continuum rather than two separate ones.

Padden and Humphries (1988) explore the concept of different centres in relation to Deaf people in their study of the culture of Deaf Americans. They describe a range of different meanings of words and signs used by Deaf people in different circumstances. They ascribe these differences to the notion that Deaf people have a different centre or alignment to that of hearing people, a different point from which they move and describe the world around them. People move in and out of different centres in different circumstances, depending on how they choose to view the world. This concept is central to Padden and Humphries' understanding of the way in which Deaf people construct their meanings, and provides a critical opening for attempts to broaden the basis for explanation and understanding. The concept clearly derives from feminist analysis and those that Black and Asian people have developed to explain their different experiences of power and oppression, and allows for the existence of a number of centres from which meanings can derive. This frees us from the need to focus on one meaning *or* another, one perspective *or* another, and allows us to construct meanings and explanations from a number of different perspectives at the same time.

This may seem an alarming prospect but is made easier by incorporating the second element in the creation of an equality between different experiences. This places deafness onto the same continuum as hearing and so creates a broader access

for both deaf and hearing people. Corker (1994), in considering the Deaf challenge to counselling provision, sets this out:

> *"Deafness and hearingness are the two ends of a vast and complex continuum which tends to be regarded as a divided community; but it is the legacy of the hearing majority that the two ends of the continuum came to be perceived as two distinct groups in the first place. They are psychologically, like strength and weakness, but two sides of the same coin, and being so, are inseparable."*

Viewed predominantly in terms of 'deafness' and 'hearing' as two experiences - with a *single* centre - the experience of deaf people is different and deviant. But viewed in a common framework, on a single continuum and with *different* centres, it is seen in terms of human experience and therefore one where personal and cultural identity are seen in terms of individual and social inequalities of power and control, which exist in others' experience as well.

Inclusion, utility and transformation

The second feature of the commentary focuses on its inclusive, utilitarian and transformational nature.

As I have said, the commentary I present here is one of a number that I can create from the issues described by people in their accounts. Each alternate commentary would use the same parameters in the framework for understanding that have been derived from the analysis but not necessarily with the same relationship between them or the same emphasis on particular features. Each individual's account deals with these in a different way. What this means, however, is that the framework should allow me to include the experiences of all participants in a single form of understanding, giving equal value to each. This inclusion is an important feature of acknowledgement and addresses people's often stated aspiration to belong and to share.

Secondly; the validity of the framework and, incidentally, the 'rightness' of my analysis and presentation of people's accounts, lies not only in its ability to include experiences but in how useful it is to others as a means of validating their own experiences and understanding the nature of meanings that are imposed on them.

But thirdly, and crucially, its validity lies in its ability to transform itself and to create new commentaries. This means that it can take account of new experiences from different people and incorporate these, by changing parameters or adding to them, to create a different framework for understanding, rather than expecting people to change their experiences or their

understanding of them in order to accommodate a fixed and closed form of explanation.

The third feature relates to acknowledgement. This is central to the way in which we understand people's experiences and the value we place on them. It takes a number of forms in the commentary. In one form, it relates to issues about methodology and the way the interview structure and the method of enquiry enables people to give *their* accounts. The richness and complexity of these accounts bears out the validity of the method for me, and people's comments about the interview structure bear it out for them. In another form, acknowledgement bestows control giving people access to their own experiences and their ways of explaining them. It also reveals meaning: to participants because they can talk about their lives in the way they experience them; and to me because it shows me the way experiences are shared and the common features in people's circumstances.

Two of the key principles in the methodology concern the importance of acknowledging my interaction with the issues raised by people in their accounts and

how I may accord respect and equality to each participant and the way they have presented their account of their experience. I chose a form of analysis that attempted to incorporate these two principles. As I describe in Chapter 3, each account was notated with issues and these were then transferred to cards and set out in a graphic representation of the account. For me, this meant spreading them out over my living room floor. I then focused on the central issue for each participant and ordered issues and parameters around my perception of their central organising mechanism - what they present in their account as the most important issue for them in relation to their experience of deafness.

This attempt to remain true to the principles of the research may create a more personalised analysis. This means that it is quite possible for readers to see other explanations in the extracts I have used in the this commentary. Sometimes, these explanations may be the opposite to the one I see. This is one of the consequences of the methodology I have chosen and has a significant impact on the outcomes of the research. It is also one of the major strengths of a commentary because of the way it *reveals* issues about existing relationships between people, issues about new relationships and questions about how people are and are not able to manage and control these.

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CHAPTER 5

IDENTITY AND CHALLENGE

From information presented in people's accounts, this commentary can present a picture of the experience of deafness that is organised around two central themes: Identity and challenge.

The struggle for identity

Running through the accounts of deaf people and professionals are stories of their struggle to find and hang on to their sense of who they are and to be free to retain that sense through the various circumstances in which they move at different times of their lives. This liberty, and the struggle to attain it, derives from people's wish to control the circumstances of their lives and their continual challenge to the people, institutions, understandings and attitudes that restrict their ability to do this.

People do not do this with a single identity defined by a single experience. People's accounts are enormously complex, incorporating not only a range of features and issues relating to their experience but also describing the different circumstances in which different features occur and the different times when people bring particular features to the fore. By attempting to describe the complexity of interaction between identities, circumstances and time, the commentary seeks to acknowledge the reality of people's experience as they see it and to shed light on the circumstances that restrict people's ability to assert identities.

It seems clear that people who are deaf - and those who work with them or share their lives - struggle continually *against* the meanings that others impose on their

experience and the way this separates them from others. They struggle *for* acknowledgement of the way they see their lives and wish to live them and aspire to connection with other people, to share and belong.

The commentary explores the various ways people use to describe their search for their identities, the different forms of restriction to people's ability to organise their lives in the ways they wish, and the different processes of acknowledgement that people seek, or are given, to resolve their sense of who they are.

> *"Yes, I can hear and understand what is going on [with hearing aids], but I still need to lipread. That is my way of life, I lipread or sign. All right, my signing skills aren't pure BSL or anything, you know like natural BSL users, but I get by... And you feel, like I've said before, so hurt by the hierarchy of the deaf world saying, 'You can't communicate with me because you're not Deaf', and you start questioning yourself, you start questioning your identity as a deaf person. Then, what the hell am I...?"* Deafened woman, age 35

> *"It can be very hurtful at times [being rejected by hearing people] but there again, you keep thinking, you keep asking yourself what you want, what do you want to achieve. Or are you just going to sit there, and let them walk over you..."* Deafened woman, age 32

> *"I just want to know enough about what I was like when I was much younger, and, like Mum was saying earlier, half of the things, I didn't realise I did all that, that all that happened..."* Deafened man, age 15

> *"I realise I have a lot to learn, and I want to be able to do things for myself. This is very important to me to know how to take control for myself, and my own future..."* Deaf woman, age 25

> *"But my experience and my background has given me the impetus to fight all these things that I have been finding through the ignorance you are treated with by other people, who are supposed to help you, people who are supposed to offer Equal Opportunities schemes, and people who say to you, 'But, believe you me, between me and you, it doesn't matter'. Well, that is an insult, because what do you mean, 'between you and me'? I have got the world to operate in, I can't just live in your little corner of the world, and in your little corner I am OK, I am equal to you but somehow once I have gone away from you, I suddenly go two or three notches down the rung because I have gone else-*

where?" Deafened Black man, age 40

"I wanted her to communicate with these people in the same way that she communicated with me, to the same level, because I knew Mum was able to look after her own affairs, really well, she didn't have any other problems, any '"social' problems, just the fact that she was a single mother, a widow, and was restricted through deafness".
Hearing man, professional, with Deaf parent, age 30

Constructing identities - being deaf and becoming deaf

It seems apparent that people construct their sense of who they are from a range of different experiences and not just from being deaf. People's identities and self-images are formed by their racial, cultural and gender experiences, from their experiences in their families and how they understand these and from what happens to them in their day-to-day existence and their understanding of why it does. Indeed, people's accounts seem to challenge our notions of 'being deaf' and 'becoming deaf', especially when we place these in the context of their other experiences.

As a general rule, the phrase 'being deaf' is used to describe a more or less permanent state of being defined in either audiological or cultural and linguistic terms and often in both. It is also, crucially, a term used by others to describe a *defining* experience, one that is seen as tending to override others and the one that defines the nature of people's relationships with others. People's accounts suggest that the state of being deaf is much more complex than this and that for

any one person it may well change over time and in different circumstances.

"I don't feel locked into a certain world. I do feel deaf, but don't feel I have to be like this or that... I think they [people] think you are either deaf, or you are partially hearing, and if you have hearing aids, you can hear..." Deafened man, age 22

"I originally <u>should have been deaf</u> [her words, my emphasis], at the age if 10 months, but they didn't find out until I was six, because when

I went for hearing tests, they thought I was backward."
Deaf woman, age 38

"At this school [at age 8], they didn't use hymn books for assembly, because the children had learnt the hymns when they first came to the school. Now, normally that shouldn't be a problem because a child would pick up the words of the hymns as they went along. I didn't, and I would just mouth the hymns, but I wasn't thinking at the time, 'I am hard of hearing' or that there was any problem with my hearing in any conscious way, but that's my first memory of being affected by the hearing loss... It seemed to create more difficulties once it was diagnosed as a hearing loss [at age 18]". Deafened woman age 38

"When I was small, I thought I was only deaf when I was at school. The only people at school were deaf people, and there were no deaf people outside of school. I just thought - and this is awful - that the school made people deaf, because only deaf people were there. I don't know why I thought this, but also that everyone else outside of the school was hearing..." Deaf Asian man, age 28

"It was awful, it took me two years to settle down there, it really hit me very hard, the worst part of my life. It was such a <u>big</u> change, I couldn't understand that. It was supposed to be a school for the <u>deaf</u>! But where was the communication? And <u>what</u> was it? I felt terrible being taken away from my family, where I felt so secure. Maybe I was spoilt, no, that's not the right word, cossetted, maybe. I felt so comfortable, wrapped around by the Deaf group, and the school broke that wrap. It was supposed to be for the deaf, but I didn't see it that way. The culture was different... I was torn apart, it really broke my heart".
Deaf woman age 28, from a Deaf family, on going to an oral deaf school.

These accounts also suggest the different ways that people 'become deaf'. It is generally assumed that people become deaf once and that this occurs when they lose their hearing. Many Deaf people do not know when they lost their hearing because diagnosis occurs later, and sometimes much later, than the loss itself. For the Deaf woman above, going to an oral deaf school it was her deafness she was losing rather than her hearing, her identity as a Deaf person that was being taken from her. She became deaf, an audiologically damaged person. People do seem to be 'made' deaf, as the Deaf Asian man above describes, by diagnosis or when the restrictions placed on people's ability to be themselves become apparent. It is also clear that becoming

deaf is not a 'one-off' experience and that for many people it occurs over and over again.

> *"It's day after day after day after day after day. I think that's maybe something people are not aware of is the constant nature the reminding to you, but also the constant things coming up that are placing barriers and creating difficulties for you every day.* Deafened Black man, age 40

> *"... she [the hearing therapist] said right at the beginning, that going deaf was not something that you get over and done with. It is something that will start every day of your life from now on. It is again, and again, and again. You won't actually ever not go deaf again. You go to sleep, and you will be hearing in your sleep, and you will wake up deaf."* Deafened man, age 50

> *"Funnily enough even though I am quite deaf, I sometimes forget that I am, and I don't think all the time, 'oh, I'm deaf, I'm deaf'. I don't. I tend to forget it, and then it suddenly dawns on me, oh heavens, you know, I'm not going to be able to hear this".* Deafened woman, age 60

> *"And often, I wake up in the mornings, and wander downstairs and do whatever, and somebody will talk to me, and I think, "oh shit, I haven't got my hearing aids in ...!"* Deafened man, age 22

For other people, they may become deaf every time they go into a shop and are ignored or patronised, or when they find

themselves in a meeting without an interpreter and are denied the opportunity to be Deaf, becoming 'hearing impaired' instead.

People describe their experience of deafness in many different ways, using different descriptions in different circumstances or using a number of different descriptions at the same time.

> *"I think, most of the time, I do, yes [think of herself as hearing] And then, it comes as a little shock when I think, oh no, I can't hear that! And I think, say, going to a meeting, a different meeting, I think, 'oh yes, I'll go there' Then I think, 'oh my god, what is the point of going?' I'll just sit there, and all I can hear is blah, blah, blah - noise' And I don't know what they're talking about. But yes, I think that I do, really."* Deafened woman, age 52

> *"I like to think of myself as hard of hearing, if that's the right word.*

With this [his hearing aid], I'm hard of hearing. Without it, I'm deaf."
Deafened man, age 58

"I have always regarded myself as hearing. I never had anything to do with the deaf until I met my husband. [Q: Do you think of yourself as deaf now ?] Not really. [Q: How do you think of yourself ?] I know I am deaf." Deafened woman, age 45

"... we were all deaf there, apart from some of us with normal hearing spouses, like I have. There were a lot of very deaf people there, and they were all singing. It's surprising, before the evening was up, my voice had gone and I was signing away like mad. And I found myself on a corner with them; I forgot about the normal hearing people. It was easier for me to get in with them, and I am convinced, if there were two groups, one normal hearing group and one deaf group, I would automatically drift off to the deaf people." Deafened woman, age 44

By thinking of 'being deaf' as a single, unchanging, defining state of being, and 'becoming deaf' as a one-off entry point to this state, we tend to construct meanings of deafness that deny the complexity of people's experience of it and their capacity to move in and out of different states of being. We focus on single issues and explain apparent contradictions in terms of people's failure to adjust to the single meanings in our model, rather than of our model's failure to accommodate the diversity of meanings in people's experience.

So, for example, we could explain the account above in terms of this woman's failure to come to terms with her deaf identity, yet this would deny her right to hold her hearing identity. We could criticise her use of language, 'normal hearing', but this would fail to acknowledge the constant adjustments she is making in the different circumstance in which she finds herself in different parts of *her* life.

This account also highlights how people's perceptions of being deaf / Deaf are connected with their notions of normality. These notions arise from language and knowledge and the opportunities to acquire and use both.

"I began to realise, seeing other deaf children, that they had a lot to talk about after being home for the holidays. I found I was getting behind with information, and it was useful to be with them, picking up information - there was so much news - so as to catch up. I felt as if I led a more normal life being with them, and also feeling that I was normal."

Deaf woman, age 45

Power relationships

A 'single state' model of being deaf may also fail to acknowledge properly the power relationships between different people and the differences in control that people are, or are not, able to exercise in their lives. The adjustment that people make to different states of being in different circumstances may well indicate people's recognition of these issues of power and control as they actually live them in their lives - and why they challenge them.

"All of life, I believe, rests in power. Racism is based on power, sexism is based on power, ablebodiedism is based on power. It is all based on that. And so the people who are oppressing you, or putting their views over and making you feel lower than them because of that situation, they get their power from doing that to you, and you feel that power by allowing them to do it. But if you said to them, 'Look, I may be deafened, but I am not stupid, and I am not prepared for you to talk down to me, and act in this sort of patronising way. Don't give me the environmental aids as a charitable deed; give me the bloody things because I need them to be able to carry out my function within the society that we all live in!' That's the way it is."

Deafened Black man, age 40

CHAPTER 6

VOICES AND LANGUAGES

What is apparent in people's accounts, which many of the previous extracts suggest, is the diversity of ideas, experiences and texts that people draw on and use to create their explanations of their experience and to determine their sense of who they are. I have called these influences Voices and Languages.

It is through Voices and Languages that we hear the variety of cultural, gender, linguistic, class and social experiences which form people's understandings and which they use to explain their experience of deafness to themselves and others. Once we can hear these, we can see that deaf people have these experiences in common with other groups of people. The *exclusive* use of headings such as 'sign language', 'Deaf culture' or 'acquired hearing loss' focuses on single parts of people's experience and tends to separate them and undervalue other linguistic, cultural or loss experiences. It is clear that deaf people do not want this separation.

> *"Nobody wants to have special rules made for them, that's why my being Black has helped me because the discrimination that I have felt as being Black is very similar to what you feel as being a deafened person. People look at you, but they don't see you, or you are embarrassment to them, they look down on you, or they just want to get their dealings with you over quickly, and then get away. So that's where the depth of understanding comes."* Deafened Black man, age 40

This variety of experiences seems to be important to the way they influence people's ability to assert their sense of identity and for the way that they either restrict or extend the range of circumstances within which they are able to do this.

Families

Families are important influences for most people. For many of us, they are the conduits through which we develop our sense of personal, social and cultural identity and they form a basic

part of the context within which we place ourselves as separate and independent beings. They introduce us to two important experiences: inclusion / belonging / sharing and separation / individuality - dependence and independence.

For some people, both deafened and Deaf, experiences of inclusion and belonging in their families provide a sense of self and confidence that helps them to move with a positive sense of their deafness into the different stages of their independent lives.

> *"Well luckily, I had a very good mother. She was perfect, and she helped me no end. I don't think I would have done so well without my mother."* Deafened woman, age 70

> *"I was born deaf, into a Deaf family. Both my parents were Deaf, and they each had one Deaf brother as well. But all the other members of my family were hearing... I'm an only child. My father's brother has no children, and my mother's brother never married, so I'm the only one... As I grew up, of course, I never questioned my deafness, never, because both my parents were Deaf, and my uncles, and one of my uncles' wife was Deaf too... I never thought about questioning it, I just accepted it because we were all the same..."* Deaf woman, age 28

> *"I wonder whether the fact that my brother had a similar hearing loss, and my mother had become by then severely hard of hearing actually combined to disguise the fact that we had problem ... I think, in fact, that we didn't have academic problems, and we didn't have social problems or emotional problems particularly ... And because of my mother, we had probably already, as you say, developed those mechanisms for coping with hearing loss; ostensibly for her, but, actually, without realising it, for ourselves as well... I'm more confident in myself. I've got a lot of experience of the subject I lecture in and I do some lecturing now (mainly in practice management), and I also feel that I can say perfectly openly, because I've accepted my hearing loss, 'Excuse me I don't hear well, so if you are going to ask questions, will you please ask them, through the chairman, or through somebody else,'*

and I will bring someone up to sit beside me and tell me the question, or "will you write your question down". I find other ways, and I don't mind saying that publicly now."

[Q: So you are finding ways consciously now in a sense that you were finding subconsciously when you were a child?]

"That's right, yes. Interesting." Deafened woman, age 40

This sense of belonging, and the acceptance that accompanies it, provides some people with the opportunity to move into the independent life of their choice and the cultural identity that they wish to adopt.

"Mum and Dad did know some signs, they were good ... but my brothers were not so good. They just pointed, and I ignored them, I wasn't interested in them ... they were hearing. My father was very good to me. He used to drive me to the Deaf club; he introduced me into the club, and encouraged me to try and mix with Deaf people. I was happy with that, and my father used to take me regularly."*

Deaf man, age 66

* (This man's use of the word 'hearing' shows one of the different meanings of the word used by Deaf people. Padden and Humphries (1988) describe the different centre of meanings that exists for Deaf people using American Sign Language, where DEAF is the norm, and HEARING is the deviation from the norm. They refer to a story told to them about an American football game between two Deaf schools where one team refers to the other as HEARING, meaning the opposite of what they are. Here, this man distinguishes between his hearing parents and his hearing brothers in terms of the efforts each made to make contact with him and to include him. For him, the least effort represents the greatest deviation from the norm. This use also introduces the notion that there are many ways of being hearing as well as many ways of being deaf.)

People are not necessarily accepted as equals in the wider independent life into

which they move as they get older; other factors may, and do, limit or deny their ability to be themselves in all circumstances, including institutional features such as racism and sexism. However, families do seem to be an important source for some sense of equality and acknowledgement with which to start their journey.

> *"When I was a child, my family didn't understand deafness, but they help a lot now... My father bought me a Minicom. He thought it was better for me to have my own, to have privacy, because it was my life, I was independent, and he didn't like interfering with my privacy. So my parents bought me a Minicom."* Deaf Asian woman, age 20

> *"My family forced me to drive because everyone else in the family could drive!... My brother told me that all of us should be able to drive, it didn't matter if you're deaf or hearing ... at one time I thought my family were thinking that I couldn't drive because I was deaf. But, actually, that never occurred to them. You see, I know my family love me. They treat me as an equal."* Deaf Asian woman, age 22

These two women's experience seem to challenge two of our popular prejudices: firstly, that Asian families do not accord their deaf or Deaf members equality; and secondly, that hearing families generally alienate their deaf children and deny their Deaf identity. It is possible to find examples in people's accounts that seem to confirm both of these prejudices but, equally, to find examples that show the same experiences of inequality occurring in white families and of alienation in the lives of children with deaf or Deaf families.

This suggests that it may not only be the fact that families are Asian or hearing that causes inequality, alienation and, for many, a premature separation from their families, but that other factors can create these circumstances.

Manufactured and imposed meanings

The central factor in these circumstances seems to be the influence of the set of meanings of deafness manufactured by others and imposed on people's ability to

assert their own identity and on their freedom to create their own set of meanings based in their experience. These imposed meanings are often implicit, emanate from undefined 'others' and are based on perceptions of the experience of deafness rather than the experience itself, as understood by those who have it. They are characterised by the denial of people's own control over the circumstances of their deafness and are the opposite to negotiated meanings, which are explicit, acknowledge different perspectives and experiences and create opportunities for control.

> *"Like, you know, if you are deaf, you can't <u>do</u> anything. You can't work, all you can do is sit down at home, still, do the housework. I don't really understand why it is like this. I still don't know, but I don't believe it".*
>
> Deafened Asian woman, age 27

> *"It [her hearing loss] seemed to create more difficulties once it was diagnosed as a hearing loss. Whether that was because, when it was diagnosed, I had to go through for me the humiliating process of getting it confirmed in hospital, well, GP, hospital, and then I was referred to Bart's in London beyond the local hospital, and then had to wear a body-worn hearing aid with a cord and ear mould, and still be a prefect at school, and stand on the platform with this thing. Now, whether that was the aspect that created more problems, or whether it was having to get used to the sound of wearing a hearing aid, which is very difficult, or whether it was just that I was beginning to face the fact, but not accepting, of being hard of hearing, I'm not sure which of these three it was. But it was certainly all those three in combination, I think."*
>
> Deafened woman, age 40

Language, identity and culture

Crucial to understanding the influence of imposed meanings and their origins is language and the way it - and people's use of it - is denied, restricted and discovered. The denial of language limits people's ability to explain the world to themselves and others and to understand the way they engage with it. People's accounts suggest that this applies in the experience of all three groups in the study and echoes the experience of other people whose language, culture, lives and identities are subject

to oppression and restriction by a dominant culture. Ngugi wa Thiong'o (1986) describes the colonisation of people's meanings and their ability to explain the world to themselves by the imposition of a different language and the denial of opportunities to use one's own. He shows how this denial affects people's perceptions of *their* reality and relates this to communication, culture and identity.

> *... Our capacity to confront the world creatively is dependent on how those images [formed by culture] correspond or not to that reality, how they distort or clarify the reality of our struggles. Language as culture is thus mediating between me and my own self; between my own self and other selves; between me and nature."*

For deaf people, the denial of language has fundamental effects on people's sense of who they are and, especially for Deaf people, forms the focus for their challenge to the imposed meanings that limit their ability to assert their identity in relation to others and to have their reality acknowledged.

> *"Knowing who I am. It's important for me to understand who I am. I once saw my face on a photo at school, with my name written on it. That was the first time I had seen my name. I thought it was magic, because I could <u>see</u> it, it was visual. I'd never heard my name before, I didn't know I had a name. But there, I <u>saw</u> it with my own eyes."*
>
> Deaf woman, age 45

As the quotation below shows, this suppression of identity and culture does not only occur in the experience of deaf people. This commonality reveals to us the extent to which imposed meanings and the control they exert and deny, influence our sense of ourselves and where we come from.

> *"On the first day of school, my teacher, Miss Mdingane, gave each of us an English name and said that was the name we would answer to in school. The Education I received was a British one, in which British ideas, British culture and British institutions were automatically assumed to be superior. There was no such thing as African culture. Miss Mdingane told me that my new name was Nelson."* (Mandela, 1994)

People, in their accounts, do not think about language as a discrete issue. Just as

Ngugi Wa Thiong'o suggests, they talk about it in relation to other aspects of their lives, including culture, family and gender - and in relation to the control it gives them to promote their sense of who they are in these and other contexts.

So, separating language into a discrete heading may make it more difficult to create these connections and, crucially, to reveal the issues of control and power that lie between them, affecting people's ability to challenge imposed meanings and to engage in negotiated ones.

For this reason, too, I have subsumed issues about communication into the general heading of Voices and Languages. This is not because I do not think communication is important but that it is too important to be extracted from other features in people's experience and especially from features of challenge and control. It is in this context that I deal with it. People, in their accounts, do use the words 'communicate' and 'communication' but not to describe an issue on its own. In the case of people using sign language, the use of these words may be more to do with the way we interpret their sign than with their actual use.

The political nature of communication and the denial of language

Let me take a little time to explore this issue further, before returning to the commentary.

Communication is a process, and a complex one which is concerned with more than just the mechanics of language, deafness, hearing, speaking or signing. It is the means by which people make contact with each other, share experiences, seek acknowledgement and understand the world.

It is also the means with which people pursue their aspirations and seek to

present their perspective and their wishes. As such, it is a political process which mediates the way that people interact with each other and the way they are able to influence, persuade or control others in order to achieve their aspirations and goals.

The second element of communication is rarely acknowledged in current ways of understanding communication and deaf people. A recent major review in this area (Panel of Four, 1992) did not contain any definition or outline of how people perceived communication. It did, however, contain definitions of the roles of the people who effect it between deaf people and others. As a result, communication was defined largely in terms of the people who provide it and what they do, without reference to the *context* within which it took place. This context comprises, among other elements, the *mediating relationship* which exists between deaf people, hearing people and the third parties who bring about communication between them, the *inequalities of power* which exists in this relationship and the *active control* that deaf people seek to take in it.

Our failure to acknowledge this second feature of communication may well be creating a major difficulty for deaf people. If we only focus, in our understanding of communication, on its mechanics and the functions of the people who provide it, we are likely to make its acquisition our primary and perhaps only goal. This may mean that we are unable, or unwilling, in our service provision to create the empowering circumstances that arise from recognising the political nature of communication - ones which empower deaf people to control the circumstances of their lives and influence others to attain it.

These issues of denial and disempowerment are central to deaf people's experience and the commentary will explore these further in due course. In the

meantime, I will be looking at language in the light of these issues of control and power, how these are asserted and restricted and how they relate to other features of people's experience.

For many Deaf people, the denial of their language and their opportunities to use it are key determinants of their sense of who they are now and they describe the ways that they sought to gain control over it.

"But when I was small, my parents didn't know how to communicate with me at all. Then, little by little, I pushed them into it, all the time, as I was growing up. They would ask me how to sign this and what's the sign for that, and so on. Deaf Asian man, age 25

"I used to sign to myself at the children's home by using a mirror, and talking to myself, to help me stay normal. I hated the six-week summer holidays there... You see, I had no one to talk to, so I had to do something to sign, and acting in the mirror helped me a lot... I also learnt not to talk to the mirror for too long - I was told the devil was in there! But it gave me the chance to improve my signing." Deaf woman, age 45

People are denied use of their language in many different circumstances, either because of specific restrictions or because of a lack of opportunities to use it.

"Being in a Roman Catholic school, we had rules and we knew it was not allowed for us to use sign language, even if we went out of school ... it was very strict..." Deaf woman, age 24

"When I left school, I eventually stopped signing. From when I left school at 16 till 1989, I didn't sign. I left school in 1976, so from 1976 to 1989, I didn't use sign. I never forgot it, though ..." Deaf man, age 33

For some, the restrictions were horrifyingly imposed.

"During the holidays in the children's home, one member of the staff helped me a lot. She would teach me fingerspell and, by using the steam on the windows, I learnt new words. But then we got caught. She got the sack, and I was punished. They put my fingers under the sewing machine and started it up next to them to stop me from signing again, and threatened to cut my fingers off, and showed the scissors to me. After that, I developed a fear of using my hands to sign ..."
Deaf woman, age 45

This issue of denial of language and the restrictions it places on people's ability

to make contact with others, share opportunities and understand the world, is one which seems to characterise the experience of both Deaf and deafened people and that of professionals as well.

> *"Fairly simple things, really. Social gatherings, any event where there's a lot of people all together enjoying themselves, is an ordeal, really. It is not something to look forward to, it is something to dread. Going to a pub for a drink with another couple is another problem; it is not really something we do anymore. I might go with my husband, because it is easier, then, to choose a pub where we know there's no loud music, and there's no fruit machines, and the two of us will be able to hold a conversation together. Going with another couple is really too much hassle. You get to a point, really, when you can't be bothered to make the effort. It needs an awful lot of concentration to have a conversation in those sorts of conditions, and at times, I just think, I can't be bothered with that anymore."* Deafened woman, age 50

> *"With most of my husband's job's there has been quite a social side, and we've been meant to go out and meet different people, you know, business people, which I have found very difficult. It tends to knot you up inside and the next time anything like that happens, you start off by, you're apprehensive of how it is going to be ..."* Deafened woman, age 45

The control of language

We can understand the denial of language for Deaf people and restrictions on their opportunities to use it because we can clearly distinguish between their language and ours. We can also relate their experience to that of other groups of people whose use of their language is, or has been restricted - Gaelic speakers in Scotland, for example, and Welsh speakers. We can see this denial partly in terms of the control that others exert over Deaf people, in their attempts to have Deaf people experience the world as they do and also as a way of dealing with the different experience of Deaf people and the reaction this generates.

We are thus able to place the denial of language that deaf people experience and the restrictions imposed on their use of language by this into a social context and

relate it to structural features of their experience which they share with others, such as class, race, culture and gender, and their deafness, which they do not.

With deafened people, we seem less able to do this as the distinction between their use of language and ours is less clear. We are looking at the way in which a group of people are denied full use of the language that they share with us and to which they previously enjoyed full access. As a result, we tend to seek explanations for the disadvantage that they suffer in their deafness and in the way that they, as individuals, react to the disabling circumstances in which they find themselves. In this case, class, race, culture and gender are individualised and tend not to be seen as part of the social context for explanations of people's experience.

> *"I think it probably depends on the person, not their sex, just on the person [whether men or woman are easier to talk with]. Some people are much easier than others. Some people can't be bothered; if you can't hear them, oh well, it's hard luck, and they will totally ignore you in the conversation. But other people will be much more helpful. I tend to think that, generally, woman are more helpful. I think they are a little bit more helpful, thinking about it, but it does depend on the person... I think women will tend to include you in the conversation. Not all women, again, but the majority of them will include you in the conversation and make sure you are hearing what they are saying. But men won't. They will just talk, and if you don't hear, then hard luck."*
>
> Deafened woman, age 62

This woman's account presents us with a number of issues. Firstly, her experience of being ignored and not listened to, especially by men, is one that many women who hear will share. Secondly, her public account of the experience - that it depends on the *person*, not on whether it is a man or a woman - is different from her private account - that the majority of women tend to listen but men do not. This may be because her public account is not informed by her gender experience but that her private account is. It also seems that the public account is the first to emerge. In the circumstances of her interview, this women was able to bring out her private account

and make it public. How often might these private accounts be suppressed or hidden by a more dominant public account which derives from meanings that focus on deafness and on the individual? And are these meanings more androcentric than we have assumed - if, indeed, we have even thought about this assumption at all?

Women who are deaf may be obliged to understand their experience only or predominantly in terms of their individual deafness without reference either to the exclusion and denial they experience as women in a male-dominated world, or to the inclusion and acknowledgement they attain in the collective voice of other women.

This restriction may be exacerbated by the nature of much adventitious deafness. Many people, both women and men, who lose their hearing later in life, lose the high tones first. This means that men's voices are often easier, relatively speaking, to pick up than those of women. For women, this may present a cruel irony. They are unable to pick up easily the voices of those who are prepared to listen to them - women - and are more able to hear the voices of those who are not - men.

Professionals seem, on occasion, to share the experience of isolation that the denial of language creates for Deaf and deafened people. This often occurs when they are in circumstances where they themselves are denied use of their language and the familiar cultural environment within which they use it. However, their isolation seems to be alleviated when they are able to find connections within their own familial, cultural or linguistic experience - just as Deaf people and deafened people can break down their sense of isolation and powerlessness when they are able to make connections between different aspects of their experience.

> *"I laugh when I think about it now. The level of ignorance was terrible. Some people were welcoming, but I was so mind-blown by it. It was a powerful experience because we, white, English-speaking people in this society, are not often in the position of being in the*

minority. I didn't quite know what to do with myself, and I was quite high, and I did feel really intrusive, as if I was an observer into someone else's life. And I remembered I hadn't been invited by these people, whose 'lounge' I was walking into. I had been invited by someone else. And I remember that very clearly. And somebody smiling at me asI walked in, and I said "Hello", and I didn't even know if I did it properly - I wouldn't have done the proper signs. He sort of said, '"Hello' and he was someone who had very clear speech and he spoke to me and asked me who I was. And I guess I really did spend most of my time with him because I could understand him, and didn't feel quite so anxious and nervous." Hearing woman, professional, age 39

"And that [going to a Deaf club] was really, again, a very pivotal experience, because I was in a minority. That's not a new experience for me, being in a minority, but it was very much a minority in that I hadn't realised how much I rely, not just on speech, but on vocalisation to give nuance of meaning, of emotion... But there is this whole thing about body language and it is really interesting because in a Jewish family, you use your body completely differently from the way you use it when you are out of the family. There is lots of touching, but you do not do that when you are with non-Jews. And it was really interesting, because in this group there was lots of quite vigourous touching, but on particular parts of the body, so I thought, 'Oh, there is a code going on here..." Hearing woman, professional, age 52

"Deaf people say I'm being over protected by my parents. I think they're wrong. My father cares about me because I'm a girl, not because of religious views or anything... My father thinks that the way Deaf people sign looks as if they're messing about with their hands, as if they're about to touch me. I've tried to tell him that it is sign language, not what he thinks. I think he's starting to realise now!"
Deaf Asian woman, age 20

These accounts indicate the way that language interconnects with culture, family and identity and how control of language gives people a sense of themselves and of empowerment in their lives.

"For me, sign language gave me information. My father is aware of this now, and he disagrees with oralism. He's let me teach him sign language. The change has happened since my father joined the NDCS and I'm satisfied now. I feel a great relief." Deaf woman, age 22

"I still miss my father, even now... I used to disappear to the Deaf club a lot, and both my parents got annoyed, and came to the club one day. The welfare officer showed them around. There were all these Deaf people signing away and enjoying themselves, playing darts and snooker

and so on. My father stood there, watching me, and the welfare officer said it was best for me to have a social life with Deaf people. He told my father not to keep me, to force me to lead a boring life and have no friends, that my parents should let me go. There I was, signing away, and suddenly I saw my parents there. I was really embarrassed, but the welfare officer told me not to worry and carry on, that he had explained to my parents and that I was right to disappear to the club. They then both realised and left me alone and went home and explained to my brother and sister ...

I still see my brother and sister often, but they both understand and leave me to my own life. I really love being in the Deaf world, it's where I want to be [this statement, signed, has many more meanings than this written translation conveys]. I told my brother and sister that I do love them, but my heart is with Deaf people. They know that, and are happy to leave me alone ..." Deaf man, age 52

Differentiation

This man's account highlights the way that language, and access to one's language, allows for differentiation and enables people to establish their independent identities.

Differentiation is often not as positive an experience as this account shows. Separation in other circumstances is painful, disruptive, alienating and fearful and is governed by the imposition of others' meanings, of language, of experience, of deafness, onto the lives of deaf and deafened people.

"My parents learnt that 'deaf' meant that they could not communicate with me. They learnt this from hearing people ..." Deaf Asian man, age 24

"My grandparents were hearing but they always tried to talk with me. They usually used gestures, not much sign, and they would get me to understand by lip-speaking, or writing notes. I never asked them why they wrote notes, I just accepted it. This was my communication, and I went to a day school. Then into _____ [a residential school for deaf children] and, bang! What a difference! I was so used to BSL all my life, till I was 11, and then went to _____, an oral school. It really hit me, and <u>that's</u> when I felt my difference."
Deaf woman, from a Deaf family, age 28

"I think it was because I wasn't able to communicate properly. [Mother: I think there had always been a language barrier, yes.] I was just afraid, afraid of getting it wrong, afraid of being ridiculed. They are all factors to make you want to shut off, aren't they?"

Deafened young man, age 15

CHAPTER 7

SEPARATION AND DENIAL

People's accounts of experiences of separation are varied, complex and revealing. For some, these experiences concern their separation from families when they are sent away to school and the realisation of an earlier alienation from their parents and siblings when they discover at school a common language and a common experience with others. For other people, separation is from a life and relationships which they have previously known and which are now fractured and infinitely harder to sustain. For professionals, separation may be from bodies of knowledge and experiences which they might be able to use to make connections between their understandings of the world around them and those of deaf and deafened people.

These experiences incorporate a wide and interconnecting range of features: disassociation, denial, difference, being alone, isolation, fear, acknowledgement, challenge, dependence, restriction, independence, connection, commonality and empowerment. There is no one way in which these features connect together and their relationship often varies from person to person across different contexts and at different times. This complexity makes them difficult to describe, yet they seem to embody the central themes of people's experience of deafness and crucially effect the meanings that are constructed from these.

The themes relate to acknowledgement, disassociation, denial and challenge. This key part of the commentary describes some of the elements in these features and some of the relationships between them. It points to the central importance of the

third party as an empowering and disempowering influence in people's lives and to the many different ways in which third parties mediate contact between people who are deaf and people who hear. Figure 1 (on page ??) acts as a map of these features and the relationships between them and may be especially useful as a guide to this section of the commentary.

Private accounts and public meanings

The key to understanding the different ways these features relate to one another seems to lie in the private and personal nature of people's accounts of issues about separation and the ways in which public meanings are created from these personal experiences. Central to this process is the existence - or omission - of acknowledgement. The creation of public meanings and the different ways in which this can be done, lies at the heart of understanding people's empowerment - their striving to control the circumstances of their lives and the ways they challenge the restrictions on their ability to do this.

The experience of deafness seems to be one that, by and large, we separate from our other experiences. This is often despite the fact that we see deafness increasingly all around us and that it occurs in most of our lives. More and more people have first-hand experience of having met, or known, deaf children when they were at school, either directly by sharing a class with them, or indirectly through having a Partially Hearing Unit attached to their school. Almost everyone has a memory of, lives with or knows a member of their family who is deaf or hard of hearing, usually someone who is older and often a woman. Yet we seem to disassociate this private experience from our public understandings and especially from the

public meanings we create and present to others. Almost all of the people in the professional group started by dating the beginnings of their understandings of deafness to the start of their professional involvement with deaf people, yet many subsequently described personal experiences of deafness that predated this. Why might people distinguish between these two sources of meaning and understanding?

There may be a number of reasons for this. One could be that our memories of these early encounters, often as children, are of being irritated, frustrated or embarrassed - or of manipulating the circumstances in which we found ourselves. We may now discount these 'children's' reactions. How can we, as mature and sensitive adults, incorporate them into our understandings now? Another reason may be that we feel these personal experiences are too narrow, in number and in scope, to permit us to use them to produce generalised notions about deafness. Yet many social workers with deaf people, who are a major source of others' understandings of deafness, base theirs on the experience of those deaf people they meet as clients of a social services department or other welfare agency. A third reason may be more crucial. This is the existence of fear and our acknowledgement of it. This fear seems to be intimately connected to being isolated, threatened and alone and is not deaf people's fear but our fear of deafness.

Disassociation

As important as these reasons is the fact of disassociation itself and its effects. By disengaging from our personal experiences of deafness, we make it difficult for deaf people to engage with theirs. We may break the commonality of experience between ourselves and deaf people and seek understandings of their experience

predominantly in terms of their *separateness* from us and seek explanations for their view of life in their *difference* from us. One of the consequences of this is that we create alternative environments for deaf people in order to explain their separation from us. This is reflected in the service structure we create to promote their interests and the language we use to describe our separateness: 'deaf worlds', 'hearing worlds', 'different worlds', 'the world of the deaf'. More significantly, by denying our ability to explain their experiences in terms of our own, we may be denying them the right to be treated in the way we expect to be treated and their right to the same opportunities that we enjoy.

People's accounts reflect their - and our - confusion about this.

> *"No, I don't feel they were connected with me. I didn't really know anybody who was deaf, so I suppose I thought it was a different world altogether. Not connected with me, personally."*
>
> Hearing woman, professional, age 26

> *"Oh no. Because I <u>was</u> hearing, it was completely different, adifferent world... I don't feel locked into a certain world. I do feel deaf, but I don't have to be like this or that."*
>
> Deafened man, age 21

Both these extracts are from people who had known deaf children from their schools.

> *"I suppose the first contact would have been when I was a small child. I was an evacuee during the war ... and the foster mother was deaf. Well, I don't think she was profoundly deaf, I think she was probably grossly hard of hearing. I had to shout as she sat across from me, and which enabled me to mutter behind her back when I thought she wasn't listening. But I suppose that was my first experience of someone who's deaf, and I lived with her off and on until I was about eleven. Thereafter, I was aware that deaf people spoke in a peculiar way, but it never infringed on my consciousness, as a sort of disability, until I was a professional social worker... I'm not sure I can remember any sort of reaction. It was a bit of a nuisance sometimes, and I constantly had to think about being on, as it were, her good ear side. And, as I said earlier, you know, occasionally it was that she couldn't hear, and I could get away with talking behind her back. So, I suppose that's about the summary, that's the sort of consciousness I had about it."*
>
> Hearing man, professional, age 55

"Yes, I was thinking about this. I think my first experience of deafness was within the family, in the sense of having a father who certainly had a reduced hearing capacity through injury. That was in no way associated with being deaf, but it was certainly in the hard of hearing range." Hearing man, professional, age 45

"People have said to me before, 'I think blindness is much worse than deafness. A deaf person can actually see what's going on around them.' But they don't really understand how a deaf person - I mean, if you can't hear anything, you see people's faces and you see their mouths move. Deaf people can often feel isolated, depressed, really get the wrong end of the stick of what's going on around them. They think that people are talking about them when they are not. Very much, they can feel it, and are completely in a world of their own. And, often, this causes chips on the shoulder, and difficult behaviour, just because they are in a world of silence, and can only watch the faces and eyes of people around them. And it may well be that person, in the same room as them, has had an awful row with their husband, or something, and is really down about that, but the deaf person thinks, 'God, its something I have done', and they can't communicate that, like we do when we are coming to work, 'What are you looking down about?', 'Oh, I had a hell of a night last night.' But that can't happen with a deaf person, and I think that's why its very, very hard for deaf people to live in a hearing world."

Hearing woman, professional, age 35

This process of disassociation is highlighted by the reactions of many professionals to the interview in which they gave their accounts. For a significant number, it represented an opportunity, often for the first time, for them to make connections between different aspects of previously separated experience - which generated new understandings for them.

"I have enjoyed it, because when I came in, I thought, 'Oh my god, what am I going to say?!' And I never prepared; I didn't want to do that. But it went quite well, because I was able to think about things, and think about what I already knew up here, but have never actually put together. Things that were inside that I have never actually thought about." Hearing woman, professional, age 50

"Yes, I think it's given me an opportunity to reflect with you how we started, what our personal knowledge base was, both personally and professionally, how much we can identify with experiences in the past, and reflect and assist us in the future." Hearing man, professional, age 55

"I wish I had more time to think about what I've done in the last few months and think about what I have actually done there, what piece of work I did, and was I doing it because the person was hearing impaired, or just because it was a social work task. I haven't really had time to look back on what I have been doing, it's actually quite new."

Hearing man, professional, age 30

"I was conscious when I was talking with you, that because of time and the remit and so on, it could have come across that all this was happening to me in isolation. But many, many other things were happening in my life. Being a social worker is a part of me. It is not the whole of me."

Hearing woman, professional, age 52

"The broadness of your approach was how I expected it to be, but I have been fascinated at my response, and I think that is something to do with the fact that I haven't ever sat down in such a way before, and thought, 'Where am I coming from?' Normally questions are asked and I deal with them here and now. I feel now that what you have done is ask me what did I feel like before I felt like I do now."

Hearing man, professional, age 42

"The fascinating thing is that you have unlocked the thought processes that have been going on for years and years. When I talk about sharing with colleagues, and being somewhat disappointed, in some ways it is because, in a sense, it would have been lovely to have actually shared some of the thoughts, and concerns, and the worries, and the experiences I have had that we have talked about, with colleagues. But I haven't felt they have been ready, or confident enough, or whatever, or responsive enough to meet me, if you see what I mean. So, therefore, I have always tended to hold back."

Hearing man, professional, age 37

"I think that what I would have liked, it's the sort of interview that I would have been quite happy if a member of the Deaf club was sitting in, too ... it's not the format, but it's the way it has been presented, yes, I have felt quite comfortable enough, and I would like them to know why, where I am going, and what's happened before."

Hearing man, professional, age 40

It seems clear from the accounts that the disassociation between personal and public ways of knowing is not something that professionals seek. Indeed, they are seeking ways to *make* connections but the opportunities to do this are denied to them and the value of making these connections - for themselves, their colleagues, for their employers and for people who are deaf - is being lost. What is also clear is the sense

of isolation felt by professionals, the importance of trust to them and the value of acknowledgement - all key features in deaf people's experience.

Disengagement is not confined to the experience of professionals. Disassociation, and the denial of personal experience, is a key feature in Deaf and deafened people's accounts and people look for different ways to assert their sense of who they are. The following extract gives a vivid illustration of this. It is from the account of a woman who became deaf when she was five years old and she gives an honest and perceptive account of her disassociation of her own deafness from that of others. She is by no means unusual and her account suggests the kind of public meanings of deafness that are created by disassociation and that the denial of deafness that tends to precede this starts with others first, before it occurs with the deaf person.

[Q: Have there ever been any other people in your family who are deaf?]

> *"Not that I can recall. [Pause.] My father had a problem, but they didn't think that was a medical thing. They said - they were terming it as a war thing, a bomb shock, or whatever it was, that damaged his hearing. But then, looking back a bit further, his brother also had a problem, he wears hearing aids. My father couldn't wear a hearing aid, a hearing aid just wouldn't have benefitted him. Then, another of my uncles had hearing aids, so he had hearing problems ..."*

[Q: What difference do you think it made, that your father was deaf, and also two of your uncles?]

> *"None, to be quite honest. It never really occurred to me. I just thought that I was the unlucky one, it happened to me, so it didn't really trigger anything off, even with the surgeons and the specialist, when they asked, 'Who was deaf in your family?' I tended to say 'no'."*

[Q: Why was that?]

> *"I honestly don't know. I can't answer that one. I don't know why I said no. I think maybe it's because my father said, 'I got it during the*

war', so I hadn't associated it with deafness." Deafened woman, age 40

This woman has only been given limited ways in which to understand her deafness and the part it plays in her life. One of the ways she may assert her deaf identity is to emphasise the uniqueness of this experience to her.

'Other-centred' meanings

The next extract also illustrates the restricted nature of those explanations of deafness that are based in difference and separation and the notion that external, or 'other-created' meanings can separate people from one another. It sets out some of the consequences of this in quite literally alienating people and in denying people the chance to build empowering reciprocal relationships.

> *"The first contact that stands out in my mind was at _____ swimming pool. I can't remember how young I was, but there was very much a wartime ethos about, and I can remember another girl saying to me, 'Those are Germans', and, I realise now - well, I was actually told afterwards. I will explain it. I said, 'Why do you say that?', and she told me to listen to the way they talked, and they were making these guttural sounds, which we identified with Germans. It's just awful now, but that's what we got, 'Don't go near them, they are probably spying!' Luckily for me, we had a very good swimming coach and he overheard this, and jumped on it, and explained to us that they were pupils at _____ school [a local school for deaf children]. But I think that, although I was grateful to him for informing us, looking back now, the way he did it, it actually made me feel ashamed, and I wasn't given any way to go towards them. I was lost in my shame."*
>
> Hearing woman, professional, age 52

This extract highlights a number of features: the presence of difference, the denial of contact and commonality, the dependence on a third party for explanation and access and what happens when explanations are offered only in terms of an unknown experience.

Fear

There is another important element in this extract, which is the existence of a sense of threat associated with difference and the sense of fear that flows from it. This points to what I believe is a key component in the process of disassociation from and denial of deafness - fear, of isolation, of being utterly alone and no longer existing in others' worlds.

People do not talk about fear all the time in their accounts. None of us do. But most people, in all three groups, talk of their own fear, of being frightened and of fear itself. I think this is very significant, precisely because people do not generally talk about their fears. It seems to suggest that fear is a central part of people's experience of deafness - and especially in relation to the way that non-deaf people construct their meanings of that experience. Mairian Corker (1994) explores the notion and influence of fear of deafness in the counselling relationship, where 'hearing' and 'listening' are essential tools. She focuses on Harlan Lane's (1992) notion of the fear of losing speech and hearing as 'existential dread', the fear of ceasing to exist, and how he links the perception that hearing people have of this state to the characteristics they ascribe to deaf people - and the meanings they ascribe to deafness:

> *"To imagine what deafness is like, I imagine my world without sound - a terrifying prospect and one that conforms quite well with the stereotype we project onto members of the deaf community. I would be isolated, disorientated, uncommunicative and unreceptive to communication. My ties to other people would be ruptured... A world without sound would be a world without meaning."* (Lane, 1992, pp.10-11)

This fear of ceasing to be is one which deafness seems to evoke. As Corker very eloquently puts it:

> *"... the prospect of losing the means of living causes deafness to become a hurricane sweeping across the inner landscape and demolishing everything in its path. Whose fear is this, and from whence came*

the hurricane?" (Corker, 1994)

But this fear is not *created* by deafness. It is a fundamental *human* fear which exists in all of us and deafness is one of a range of conditions and experiences that evokes it. However, because it is so fundamental and threatening to our sense of being, we are likely to seek to avoid it and to distance ourselves from any condition or circumstance that evokes it - or reminds us of it. We are likely, then, to disassociate ourselves from deafness and deaf people and to seek to do this by constructing meanings of deafness and of the experience of deaf people that prevent this fear from being generated. These meanings may seek to deny deafness and not to acknowledge the fear that it evokes and this commentary focuses on this aspect of it.

It is clear from their accounts that people struggle with their fear and do not necessarily seek to deny it or the experiences associated with it. People most often talk about fear in relation to isolation and aloneness, to feelings of threat and being threatened - and to the sense of powerlessness connected to these feelings.

> *"I felt really nervous because I went into the room and they were all pointing and looking at me and I got the distinct impression that they were pretty offish and I had seen one girl going, 'Hearing, hearing' and I thought they did not want to know me. Of course, I was smiling and trying to be friendly, but no. They were a little community of their own, which I did not realise at the time, and because I was hearing, I felt the odd one out. I felt left out. I was pretty scared, and they were waving their arms furiously. One was saying, 'Hearing' - she is a client, actually, and I know now that she has learning difficulties, but I didn't know at the time - and she came up to me and pushed me, and I was a bit frightened. But then I got to know people and they came in - I don't know whether it is because I have started to learn a bit of signing that people become more friendly, or because of my personality, I am not quite sure. But as time went on, it got better... I think it was because I couldn't communicate with them. Whether they felt, 'What is she doing working for social workers with deaf people, and she can't sign?', I don't know whether it was that. I did actually feel a bit frightened at first, but now it is different again. I am not frightened to go into a room where deaf people are, where I was before. If they are sitting in their meeting, and I had to make a cup of coffee, I would*

shoot through the room, frightened that anyone might sign something to me, and I wouldn't know what they meant, and I would feel stupid, then."
Hearing woman, professional, age 26

"And I can remember some little while before, I started going into London on the train, being quite frightened, although I was now into my teens. The man was clearly deaf, but I was trying to make sense of what he wanted, and not thinking, 'This man needs help', but rather, 'This man actually needs securing somewhere', because I was frightened of him, and he looked as if he was out of control. He wasn't, but he just couldn't make himself understood, and we were handicapping him."
Hearing man, professional, age 41

"... to be honest, it is not so much that they aren't interested. From my experience, I would say that they are more frightened. Where my husband works, there is a group of deaf men there, and they don't speak properly, and he never spoke to them much. But when I became deaf, him being with me, he gradually started, and has sort of conversations. He is not frightened of them so much, now."
Deafened woman, age 45

A number of professionals talk about ways that they have challenged their fears. Often, they have done this through work with deafblind people - which, for many of us, represents an ultimate experience of isolation.

"... I only learnt to cope with deafblind [sic] when I went on a course here, and we had to choose a topic, and I decided I was going to try and combat this deafblind thing, and did a lot of research on it, a lot of learning, a lot of reading. I then did a project on _____, and spent a day at _____, and I had my lunch and tea with the deafblind, and I tried to communicate with them, and I got over that a little...

"The actual day visit was superb. It was so easy. It was the drive going there that was terrible. It was worse that going for an exam. I was petrified. I think probably I was being very selfish. I was petrified in case I would freak out and look a fool. And then when I got there, it was so easy, there were no problems, none whatsoever... What was easy? That I didn't feel any rejection for them. I didn't feel that awful pity that I had felt at _____. There, I was just so devastated that people had to live like that, just how cruel it was. In fact, I was probably feeling that maybe euthanasia should come into force, and maybe they should all disappear, that one shouldn't have to live like that, this terrible draining of - it wasn't exactly empathy I had, it wasn't pity I had - pity is not a nice feeling..."
Hearing woman, professional, age 57

"I think it would have been quite impossible to have acquired any real emotional insight. I would have got an intellectual insight, but to actually get the feeling level of it, I wouldn't have acquired it had I not seen John in his factory, if I had not met people whose sight was deteriorating as a result of Usher's Syndrome, or people who have had hearing and sight which has been deteriorating and the trauma of that, or the lady who was increasingly depressed about what was happening to her, in contrast to an old lady we met who had been born totally deaf and blind, and had lived in sheltered accommodation, and had got used to it, living in sheltered accommodation. There was a range of people that we saw, but I would never have understood the dynamic, and the coming home and offering a thousand and one blessings that I had still got my senses working. I mean, music is a passion outside work; to be deaf and not to experience music would be absolutely devastating. It was getting in at gut level..."

Hearing man, professional, age 57

"For me, one of the big questions before I went on the course last year was 'Would I be able to work with an offender when it was child abuse?' I did not know the answer to that question. The other question was about mental illness. Would I be able to work with male, mentally ill people who were violent, because I was very, very scared of violence. I hate violence. And those were the two key personal issues for me going on the course. So, I requested my first placement with the child protection team, working with an offender, and the second one in the Department of Psychiatry. It tied in very much with the image of Judaism, the constant grappling to understand ...

"Well, it is not so much that I am not going to let this beat me, it is 'I am going to understand whether this is right for me - I have got to find out about myself', because when I am actually with clients, I should not be putting this on them. If what is happening is about me, and my fear of being stood over by a man, I have got to own that, because unless I am doing that, I can't really assume his responsibility and his problem."

Hearing woman, professional, age 52

These accounts of challenge demonstrate the link between personal experience and public meaning and the importance of acknowledgement of pain and fear. However, if this is something that professionals do only in exceptional circumstances, how do other people achieve this and how far are they enabled to do it? I shall return to this issue when I look in more detail at acknowledgement and denial.

'The only one' - isolation and aloneness

Fear seems to be clearly connected to feelings of isolation and being alone and to the inability to make contact with others that creates this sense of isolation. Being lonely, being 'the only one' and being left to be alone are all experiences shared by Deaf and deafened people and by professionals in circumstances that are sometimes different and sometimes not.

"I was actually invited by the lad to go to the Deaf club and it was just after Christmas and I didn't know what to do. And he went off and I felt really alone, and isolated... I didn't know what to do, no idea how to order a drink or anything, and almost afraid that someone was going to come up and talk to you, ask you a question, 'Sorry, but I don't understand.' Really out of my depth." Hearing man, professional, age 27

"When I left school, I was frightened. I got a job a few days after leaving school and felt very shy standing at the bus stop. I was doing things for myself now and I panicked. Because of being deaf, before, in school, when we went out we usually went out in a group, holding hands. When it came to paying my fare, everyone was looking at me. I felt really embarrassed. I hated that. I felt stupid and I hated people looking at me. I was embarrassed to speak, to explain I was deaf, that it was different for hearing people.

"But now, I don't care. Slowly things have improved. I still feel a bit frightened when I go into a pub with my sister, say. If there's a disco, boys talk to me, then find out I'm deaf and they don't want to know me." Deaf woman, age 29

"And it is quite frightening. I know I found it frightening when I have had very weak communication skills and I still find it frightening in some situations where I feel totally inadequate because this person has such good communication skills and I am quite sure that other professionals, yes, are very threatened because of their own inadequate communication." Hearing woman, professional, age 32

"When I was in school I was the only deaf girl, anyway. When I went to a local school I was the only one in the whole school. I was the first one, too. When I went to the High School I was the only one in my year. So I suppose that's why I felt a bit left out of things, because my sister, she had a friend who was deaf as well in the same class, so the two together had each other." Deafened woman, age 18

This sense of aloneness, of being the only one, is a key experience for many

deaf people. It is significant that it is also one that is shared by professionals, working across a range of services - education, health, social services, voluntary agencies - who report that their lives as professionals are marked by isolation and by being cut off from others. This is likely to have considerable consequences in terms of the information they receive and their ability to place their working experience with deaf people in a wider human context.

"To a certain extent, but I was left on my own; that, yes, I was acting as a consultant to the area teams, to the social worker and that I would hold the difficult clients, as it were - not difficult clients in itself, but difficult problems surrounding them - and that I would be trying to develop the service. But that was it, then. Very much, it was over to me and I was on my own and I did my own thing, really. There was a line manager I went to that was actually in charge of some other areas of work as well. But I very much was on my own after that."

Hearing woman, professional, age 36

"I am not part of any one establishment. I am part of the service for deaf and partially hearing children but I am actually not amongst that group of people very often, apart from staff meetings and the odd training day. I am out there on my own and the danger is that I can become very isolated and detached and not receive information from that source."

Hearing woman, professional, age 32

The aspiration to human contact is one of the most important features of people's experience of deafness and, for many, their loneliness or aloneness is not about a lack of communication but the loss of human contact. On occasion, people's loneliness is not caused by their deafness but is certainly exarcerbated by it.

"Their depth of fragility and unhappiness, the difference between those who cope and those who don't, the enormous gap between people with the same audiogram, with the same hearing aids and their perception of how it is for them and the huge difficulties that they all have in terms of understanding and getting people to understand them and having the same interaction and human warmth and, as we were talking about the other day, the lack of strokes that they suddenly get because they can't hear. That's when you learn about deafness. It's the 29 year old that I saw the other day who has acquired a deafness and you are talking to him and you discuss noise, you discuss hearing protection, then gradually you think, 'This guy's never talked about this before', and

you gradually work on him, and get him to open up, and you say phrases like, 'It gives you a couple of problems, and it makes you feel a bit different, sometimes you feel -,' and then he says '- lonely'.

And you've got this young guy who has got an acquired hearing loss, which isn't severe, who is married with two small kids, who has a full-time job and he is telling you that his big problem in life is that he is lonely. That's when you begin to understand about deafness."

Hearing woman, professional, age 35

"I got married, I had my children, my father died before the third son was born - my mother died eighteen months later... And all of a sudden, I felt on my own and I was totally lonely for the deaf. And the first thing I did was go down _____ and join the Deaf club... It is impossible to describe it. One could say it was just in the blood, but there is an empty feeling, not the empty feeling of losing one's parents, it was something different. It wasn't bereavement [but] an empty feeling like when you are hungry. It was an empty feeling, yes."

Hearing woman, professional, from a Deaf family, age 55

"I was born in _____ and went to an oral school there, until I was four or five. Then I went to _____ school where I was allowed to sign. I left school and didn't have any friends [at home], deaf or hearing. It was awful. Until a long time after, when I was about twenty-six, I escaped and lived in a flat in _____ and met some Deaf people who signed. It was where I met _____ [her partner] and got married..."

Deaf woman, age 40

"So, if I haven't got a definite place to, I don't go out. Therefore, I am finding myself, well, it's alright in the summer because I can spend hours in the garden but you can so easily just give up and stay home. I mean, I watch TV for hours and then I knit and I sew, and I am lonely. Merely because, having worked all my life, all my friends were at the hospital, so I didn't make friends around here, not for any other reason than I was never home to see them... So you find it very lonely."

Deafened woman, age 62

Isolation is incredibly disempowering and people do not seek it. Indeed, they challenge it and strive for the connection and belonging that empowers them.

"Well, there was two of us, so I wasn't on my own any more. In a class of 20, if two of them are deaf, well, that's quite a significant proportion and the teacher took us seriously." Deafened woman, age 18

"We had a lot of very unhappy times. It is terribly lonely and as a youngster I got left out because if you couldn't keep up with the others, the conversation of what was going on, you more or less had to step

back into the background and people certainly didn't put themselves out to talk to you. If you didn't understand, that was it ...

This a hearing person wouldn't understand, just wouldn't understand, that you don't want to be cut off from ordinary people. And that is the whole trouble. A deaf person just wants to be an ordinary person, not a thing apart."
Deafened woman, age 55

Separation

Separation is a defining experience for Deaf people and a significant one for deafened people, as it is for all of us. At one level it seems to take place in very different circumstances for Deaf people to those in our experience, yet there are considerable similarities between people's experiences. These point to commonalities of understanding and meaning with which to address issues of opportunity, equality and empowerment - and create acknowledgement.

"I was four years old, and it was a horrendous experience when I started. My mother took me out for a drive in the country and we went to see this school and we were upstairs in the dormitory where the younger children would stay - I think they were between four and ten - this massive dormitory. And I was there having a look around and talking with some of the children that were there and I turned round and my Mum was gone. She had vanished. I can still see it now, I had this bed and the stairs were directly opposite and there was this polished wooden railing around it with spills and the stairs going out that side and there was this wizened little old nun on the stairs, and I started shouting, screaming and crying, ranting and raving, and she said, 'We don't let bad little girls see their Mummies'. So, that was my introduction to boarding school."

"One day, the teacher called to me and I didn't turn round. The teacher couldn't understand. A week later, I went to the doctor and he found out I was deaf. I don't remember this, my mother told me about it. She was really shocked. I moved to another school in ____-_____, where my mother and father left me, and went home. I can remember shouting, getting angry at the teachers. I was about six. I argued, I wanted to go home, I was devastated and complained. And I hated sleeping at the school... I remember not knowing why my parents had disappeared. I couldn't believe that they would leave me behind. I just didn't understand..."

These two accounts are remarkable, amongst other features, for the similarities of images, of language and of experiences recalled. The first is from a hearing woman, a professional, and the second from a Deaf man, both in their thirties.

The continuation of this man's account illustrates a common and important feature of Deaf people's experience of separation on going to residential school - the discovery of language. It also illustrates a second key feature, the realisation of an earlier separation or alienation from their family. This marks, for many people, the beginnings of their understanding of how their deafness, their difference and their Deaf identity is denied and of their challenge to this.

> *"... I know that when I moved to the bigger school, I started to sign and my parents couldn't sign. I tried to sign with my family but none of them would and I got really angry. I felt happy going back to school, then, where I could sign ..."* Deaf man, age 30

People's experiences of this are not all the same and they contain a number of strands, some of which they have in common with people who hear and with deafened people. These relate to aloneness - being 'the only one' - to isolation, to denial to acknowledgement and to the assertion of identity.

> *"As a child, I was separated from my parents and went into a children's home. It's a strange memory, that, of seeing people all talking fast. I felt lost and frightened, and I didn't understand the use of talk. I wondered how to talk... One day, something unusual happened. I was given some new clothes at the convent. I remember waving goodbye to my brother and crying. Then I was by myself on a loud train and I screamed. I was lost and frightened. When I got to the school I saw other deaf children and realised they weren't talking either. I picked up a sense of understanding through their eyes, a contact between us and felt we were the same."* Deaf woman, age 45

> *"... the first eleven years, I was happy in my deaf school, with my Deaf family, in the Deaf community. I was <u>very</u> happy. I even played with neighbours' children after school and their being hearing was no problem. So, really, I see my life of those eleven years as being different from my life in the next five... Being in a boarding school made a lot of difference, like I'd been taken out of my own circle and put into*

a hard, cruel world." Deaf woman, age 28

It is clear from these accounts that the experience of being left and being separated, is a vivid and painful one and that separation in these circumstances involves a number of different experiences, some of which can have positive consequences. However, this pain occurs and is recalled, notwithstanding the subsequent discovery of language and the sense of belonging and human contact that going to boarding school opens up for many Deaf people.

Another feature of these accounts, from both hearing and Deaf people, is that they are given by people who seek to keep in touch with their emotions and have found ways to approach their pain and their fear so that they can give meaning to their experiences and live with them. This acknowledgement is often not present in the attitudes of others or in the meanings they impose on people. What happens when people are not able to do this? In a number of accounts, particularly those of Deaf men, memories of residential school experiences are less clear cut and accounts of them may appear confused and contradictory. People often remember the positives, relating to their discovery of sign language or a sense of belonging, but seem to skate over the painful memories associated with being left, being alone and being vulnerable.

"My school was in _____ . I liked school, it was good, but very cruel. It was rather like a prison ... you couldn't go home very often, only at Easter, in the summer and at Christmas, and when we went home it was very boring ..." Deaf man, age 66

For one man, the memories seemed so upsetting that he stopped signing and bowed his head in silence and stillness, still apparently overwhelmed by these experiences and unable to find the language to explain them to himself or to others.

These experiences seem to show that going away to school involves children and their families in a number of different forms of separation. These different forms

highlight issues about denial and acknowledgement and their relation to control and empowerment. The denial of deafness, often imposed by other created meanings, restricts people's opportunities to have their experiences acknowledged or even their ability to acknowledge them to themselves. This denial, which is at heart a denial of identity, promotes a sense of powerlessness, restriction and anger and sets up the challenge that both Deaf and deafened people mount against that sense and against the circumstances that restrict their ability to be themselves.

Firstly, there is their separation from the familiar circumstances in which they have grown up and which constitute their first experience of belonging and human contact. For some, such as the woman above from a Deaf family, this sense of belonging is well-developed and has meaning for her partly because she has a language with which she can describe it and explain it. Her sense of loss is very acute. For others, their sense of belonging may come from close family relationships, where parents want to make contact with their children and create connections and sharing and use that as the basis for their communication with their child, rather than any formal language. Their sense of loss may be equally acute. It seems clear from people's accounts that many experience as children the pain of separation from their familiar sense of belonging and that this pain is rarely acknowledged - by schools, by families, by themselves or by Deaf people as a community. Why might this acknowledgement be withheld?

Secondly, there is the alienation which occurs when deaf children discover a language and a sense of belonging connected with it, *after* their first experience of separation on being sent to boarding school. Here, they meet other deaf children either for the first time or for the first time in a group. They discover a language

which they share with others, which enables them to talk about their experiences, which they share with others and find that they are not alone, that they are not 'the only one'.

The discovery of what is often the second language that deaf children come across, which becomes their first language and a second experience of group belonging, which becomes their primary cultural identification, may expose for deaf children the limitations of the linguistic and cultural experience they have had in their own families. This may generate a sense of anger and blame which is directed against families and parents. This challenge is directly related to the realisation of difference and the development of individual identity - and how these have been denied.

> *"When I came home, I told my mother I didn't like school, that I didn't want to go back to school. School and home were different and I had to behave differently. There were different ways I had to behave at school and at home."*
>
> Deaf man, age 66

It seems clear from people's accounts that they do not want to be alienated from their families, that what they seek is the confirmation of their independent, different identity and wish to separate from them for that reason - the same reason that any of us have for wanting to separate from our families.

I have used the following extract before, in another context. I want to use it again because it is so illustrative of this particular issue as well. Doing this demonstrates the richness and complexity in people's accounts - and confirms the accuracy of Walt Whitman's observation!

> *"I still miss my father, even now... I used to disappear to the Deaf club a lot and both my parents got annoyed and came to the club one day. The welfare officer showed them around. There were all these Deaf people signing away and enjoying themselves, playing darts and snooker. My father stood there watching me and the welfare officer said it was best for me to have a social life with Deaf people. He told my father not to keep hold of me, to force me to lead a boring life and*

have no friends, and that my parents should let me go. There I was, signing away, and suddenly I saw my parents there. I was really embarrassed but the welfare officer told me not to worry and carry on, that I was right to disappear to the club. They then both realised and left me alone and went home and explained to my brother and sister. I still see my brother and sister often, but they both understand and leave me to my own life... I told my brother and sister that I do love them but my heart is with Deaf people. They know that and are happy to leave me alone ..."

Deaf man, age 52

One of the key elements in this extract is the importance of acknowledgement - of difference, of language, of independence, of self - which allows this man to become himself *with* his family and *apart from* them.

So, what might happen when acknowledgement, particularly of the pain and anger associated with being left and being denied self, is withheld?

The denial of humanity

As we have seen, many people recollect the pain when they were separated from what they knew and where they were, however well or poorly developed this was. If the pain associated with losing this is not acknowledged, the child may deny the experience in order to deal with the pain, especially when he or she has discovered a new sense of belonging with other deaf children at school. Equally, the failure to acknowledge children's anger about being denied their language may well mean that they deny all previous linguistic experience. So, children are not alienated from their families by the discovery of sign language and a Deaf cultural identity but by an inability to deal with their pain about the loss or non-existence of familial and communal belonging and with their anger at being denied use of a language which can help them to create this sense of belonging and to assert their different identity. This inability is not theirs, nor is it their family's. It is created for them by meanings of

deafness imposed from outside the experience of deafness, which alienate them from their families, separate them from us and deny the commonality of our human experiences. This has horrendous consequences for their families, for us and for them.

> *"... he wasn't identified as being profoundly deaf until he was turned two. It's just so painful. He was a longed-for child and his parents so much wanted to do what was right and they put themselves completely into the hands of the professionals and, as I see now, from my perspective now, they were absolutely bombarded with the belief that there was only one way forward and that was oralism and they believed that and they took it on. And looking back and knowing what I know now, I think that was responsible for so much additional pain and suffering, because they couldn't communicate with their child and their child couldn't communicate with them ... and what that meant in day-to-day terms was enormous levels of frustration, enormous levels of day to day management problems, like the child having what may be labelled as 'temper tantrums', but they were being stopped from seeing his needs and being able to meet his needs. Their own needs were completely set aside and, when I was with my grandson, I just felt - I've never thought of it like this before - but all those initial feelings of shame and guilt about my not being able to communicate with a deaf person coming up again. And I wanted to just look at him and talk, but absolutely everything I did, my daughter and son-in-law would, say, 'No, no, you are doing it wrong', because that was what they were experiencing from the professionals. So that really was my next deep encounter. I just felt so bloody useless, either to help the child, or my daughter, or my son-in-law, so I just tried, whenever I was with them, to, first of all, say to them, 'Let me know if I am doing anything wrong, but can you let me know in a different sort of way'."*
>
> Hearing woman, professional, age 52

This extract sets out starkly how others' meanings deny people control over their lives, how they create dependence and powerlessness and how they create multiple forms of separation -of grandmother from grandson, of mother from daughter, of parents from child and, ultimately, of the deaf child from his own deafness.

What is most disturbing about the effect of these forms of meanings, as illustrated here, is that they seem not only too be based outside the actual experience of deafness as lived by deaf people but also outside of the human experience we all share.

For children, these can be taken as centring on the importance of:

> *"the stability and the security, the loving and understanding care and guidance, the warm and compassionate relationships that are essential for the full development of the child's own character, personality and talents."* (The Welfare Principle, Children Act 1989)

It is this aspect of separation that is central in deaf people's experience of deafness: the denial of their humanity which arises from the denial of their difference and of their commonality and the lack of acknowledgement of their experience and their selves.

CHAPTER 8

ACKNOWLEDGEMENT, HELP AND POWER

The final part of the commentary explores the importance of *acknowledgement* to people's ability to be who they want to be and to challenge the conditions that restrict their opportunities to assert themselves in the same range of circumstances as any other group of people in society.

It looks at the importance of *information* in this process of acknowledgement and how this enables people to take control of their lives, in both an individual and social context.

It examines help and helpers and in particular in relation to the role of the *third party* in the lives of deaf people as a means of creating acknowledgement or of compensating for the lack of it. It focuses on ways in which deaf people are able to use help and helpers to make connections, to be included and to take control, and the ways that help and helpers separate deaf people from others, create isolation and deny control.

It looks at the notion of *moral power* as the means by which people exercise their control: what this is; how it develops in reciprocal relationships; in what circumstances it is exercised; and what happens when reciprocal relationships are denied and it is exercised on people's behalf by others.

Acknowledgement

Acknowledgement is a central feature of people's accounts. It is apparent, first

of all, in people's willingness to talk about their experiences, which are often very painful for them, and where they sometimes talk about issues or experiences for the first time. This is a vivid reflection, mainly for Deaf and deafened people but also for professionals, of their sense of being ignored and unvalued and of being powerless and lacking influence or control. The experience of being listened to is crucial to people's sense of being acknowledged as the people they are.

> *"I wish that I could come up with something that would be helpful to deaf people, but I do go right back to what I was saying. I honestly think that people who are hard of hearing don't want to be known as hard of hearing. They just want to be ordinary people, and therefore they are not asking for help. They don't ask people to repeat things if they can possibly help it, they would rather miss out. The general public, the hearing public, I don't think they would ever understand how much the deaf person wants to be included. That's the truth."*
>
> Deafened woman, age 63

This woman is talking specifically about the experience of people who have lost their hearing, yet the issues of connection, sharing, inclusion and independence that she raises are just as applicable to other groups of people.

> *"It's good to mix with hearing people. Being deaf cuts me off from information. I get better information from older Deaf people and younger hearing people ..."*
>
> Deaf Black man, age 28

> *"While I was living at home, I felt very disturbed and angry, because we we're not allowed to sign. You see, I'm one of twins and we're both profoundly deaf. My sister suffered and I felt hurt and I supported her. Mother used to get really angry if we signed and I'm even angrier now because, you see, Mother signs now! It was really frustrating, you see, Mother talks and signs better than me now. Also, we weren't allowed Deaf friends in the house. Our hearing brother was allowed to have all his friends in the house... It was awful. I left school and had no friend, nor any contact with any Deaf friends. It was a terrible experience, ten lost years... Our brother changed our lives, opened them up. He became aware that my sister also had friends and it was him telling Mother to let us bring our friends into the house ..."*
>
> Deaf woman, age 66

Acknowledgement takes many forms for people and they describe a range of

circumstances in which it occurs. It reveals identity, giving people the chance to be themselves; it creates the conditions for inclusion and connection, allowing people to share and belong; and it releases people from the control that others exert over them. For some, it comes with the admission of the fact of deafness, either by self or others, and is about naming and seeking to know. For others, it arises from the realisation of difference and the ability to understand experience and is about making deafness public and collective, an experience that can be shared with others rather than it remaining only private and individual, one that is isolated and isolating.

> *"Me, personally, I'm still not involved with the deaf in normal life. At work, with normal hearing people, there are a couple of deaf people. I play sport, but there are no deaf people there. The only thing that took me some doing was to admit that I was deaf. I used to be very embarrassed about it, but then, at that time, I felt it was only me that was deaf, no one else was deaf... You are obviously trying to find out what different people's views are. You probably ask the most basic questions, and things roll from one to another, and then they tie up, I suppose. You'll probably go away and think, Oh, she's said the same as such a lot have said in one particular area', which is probably interesting, really, because people like myself are not aware of certain things that we've all got in common."* Deafened woman, age 38

Naming

Many people, both Deaf and deafened, talk of their wish to find out about their deafness, either when it occurred, what caused it or what it was called. For deafened people this may be related to the desire to see if there is some way of reversing their deafness, whereas for Deaf people this is not a feature. For both groups, though, the acknowledgement of the physical reality of their deafness is clearly an important part of defining their sense of who they are and of taking control of this aspect of themselves.

> *"As I grew up, I didn't know what had caused my deafness. I went to*

see my sister and asked her if I was born deaf or hearing."
Deaf man, age 52

"I wanted to give it a name, and a disease, if you like, a disease name. In fact, there is a disease name, but I can never remember what it is!"
Deafened woman, age 38

"I asked my mother to tell me why I was deaf, and when I became deaf. At first, she refused to tell me, but eventually she did. I think she should have told me before, I feel happier knowing now". Deaf man, age 35

"So I went back to my own doctor because I wasn't having a hearing aid, I wasn't having any problems with my ears, and I said that I just wanted to know about my deafness, whether it was going to get better or what had caused it. Looking all through my medical records, he sent me back to the hospital". Deafened woman, age 61

... I suppose it is not knowing that is worse, isn't it? If something has happened and you don't know why it has happened, that is more worrying than what has caused it." Deafened woman, age 52

"I just want to know enough about what I was like when I was much younger and, like what Mum was saying earlier, half the things I didn't realise I did all that ... so that would be quite useful, but I'd have to ask Mum lots more questions than that, and I don't think Mum would like to do that ..." Deafened young man, age 15

"My brother and sister know what happened to make me deaf, but they won't tell me. They'd rather not tell me." Deaf woman, age 21

It is clear that people often have considerable difficulty in establishing the physical reality of their deafness which for some is through late diagnosis but for many others is because of the reluctance of others to attribute cause or discuss how and when deafness occurred. The young man above was able to discuss these issues with his mother and so build up his picture of himself this way, whereas the young woman was not able to talk with her family, so had to build her picture in other ways. What is clear in both these extracts, though, is the awareness of these two people of the reluctance of others to discuss deafness and that there are reasons for this. For families, particularly parents and more particularly mothers who seem to bear the

burden of explanation, there is likely to be a complex array of emotions, of guilt, of anger, of frustration, of fear.

> *"... now, my son was the first contact with deafness, and what I can remember about it is anger, sheer anger not just at the help I didn't get, but anger at myself for being so docile and timid and accepting of what I was told. That is something that I would never do now, but as I say, that isgoing back 30 years. I should have thumped the doctor's desk and said, 'I want a second opinion'."*
>
> Hearing professional, with deaf son, age 51

> *"I remember being thrown into an absolute guandary, because I wanted them to tell me Michael was deaf, because otherwise I didn't know where I was going to go. This was really the last resort; we had been everywhere else. And, although I <u>wanted</u> that, and after three hours I was given that, I just remember feeling so overwhelmed. In fact, I couldn't hear a word... I couldn't hear a word he said, because all I kept doing was looking at Michael, sitting at this table - he's deaf, he's deaf. So part of me was amazed, and the other part wasn't, and I thought, 'goodness me!' I just didn't realise the degree, the deafness, and what it meant, and from then on... So I just remember, because then it was a question of getting to know Michael all over again. He couldn't say, 'Mummy'. I remember sitting there, saying, 'Say Mummy', and he wouldn't say Mummy. All the things I kept trying to get this kid to say and he wouldn't say a word. But then suddenly, you see, you're given these hearing aids and I have got to get to know him. He was four years old and I don't know him, suddenly ..."*
>
> Hearing woman, with deaf son, age 35

Both of these women fought long and hard for their children, and longer and harder than many of us might, yet are still left with feelings of anger, helplessness and regret. They have been given the responsibility for their child's deafness, even though it is not theirs. Their children's deafness has been made private and individualised on to them. They seem to be carrying not only their own feelings about their child and his deafness but everyone else's as well. Delays in diagnosis, which are still more common than we assume, may well be due to more than just inadequate screening procedures and be rooted in our deep-seated reactions and feelings about deafness itself and the fear of isolation that these create. Apart from parents, it is often others who

acknowledge deafness first.

> *"....and then he started nursery school, and the nursery teacher took me to one side and said, 'Look, I really do believe that Michael has got a hearing problem', and from then on it was basically just fighting shire to get a diagnosis, but it was a long hard battle."*
>
> Hearing mother with deaf son, age 35

> *"When I came home from school. I used to play football with hearing children. They used to touch me or tap me to tell me to move, or whatever. They were the ones who knew I couldn't hear. The children knew, but not my parents, they found out later that I was deaf ..."*
>
> Deaf man, age 44

This wish to find out about deafness and the fact that this is a very common wish, suggests the challenge that Deaf and deafened people want to pose to the denial of deafness and the restrictions this imposes on their sense of who they are and what they can do.

> *"The fact is, you still get treated badly, you are still made to feel like dirt or worse in the street, by a look or a glance or a comment. People don't have to use swear words at you to put you down and make you feel that way. You could say, that's because you have an inferiority complex, but it isn't like that. The situation is the opposite way round. If somebody everyday said to you, 'You are stupid because you are white'. everyday, everyday, everyday, you will go through feeling, 'Why are they saying these things? I don't feel that way! But then, gradually, over time, maybe late at night, you will say; But am I? Then you start believing it and, before long, you find that your motivation to achieve anything is undermined in doing that".*
>
> Deafened Black man, age 40

Ownership and acceptance

There seems to be both a desire to own one's own deafness and acknowledge it as part of one's self, and a demand for it to be publicly accepted. This form of acknowledgement - public acceptance - is related to people's aspiration to belong and be included and takes place in different circumstances for different people. People's challenges to the denial of their deafness as a different but equal experience and to

the circumstances of exclusion that arise from this, are rooted in people's experiences of marginalisation and oppression. For Deaf people and Black people, for example, their challenge to the denial of their equality and their exclusion from the same range of opportunities to participate and belong that are available to any of the rest of us, starts from a life experience of oppression and marginalisation. For deafened, and especially for white deafened people, their challenge is often to the loss of their equality and inclusion, which occurs along with their loss of hearing.

> *"First of all, I should say, to go back a little bit, about the middle 1950's, when I returned to the bank after the war, the medical officer picked up the deafness and so the deafness came on my records and every time I had an interview with the personnel manager there came a point in the interview when that happened, and I would be put off my stroke. I couldn't necessarily hear what he was saying, depending on how well he happened to speak. And so I was quite delayed for quite a long time - in my view for that reason - before getting my first promotion. And then, fortuitously, a director of the bank came to visit the branch, Sir George Shoestock, and the manager told him about the problem. So, when he interviewed me, he had a voice like a foghorn! You could hear him, I don't know throughout the Home Counties, I should think! So I had no difficulty hearing him. 'I hear you're deaf. I'm deaf. Doesn't stop me. I just speak up and everybody speaks up to me, as well. I can't see that you are deaf at all.' So, that was that. One month later, I got my first promotion and from there on, the ball was in my court."*
>
> Deafened man, age 67

> *"Me and Mary go to a hearing pub, because the landlord signs well. It's really great to have someone who can sign well. He's never embarrassed to sign, he's very open, and there's others who are hearing who sign as well... More and more hearing people wanted to learn how to sign in that pub ... they never mock the deaf, they're very warm and friendly."*
>
> Deaf man, age 52

> *"... I find I cope much better in that shop [Marks & Spencer] than I did shut in that little happy family office... Because they encourage you and they help you, and they won't let you got upset about it. They say, 'We employed you when we knew you were hard of hearing', and watching me work hard on shelf-stocking and looking at all my past work records, even before I was deaf when I used to be a cashier when I had normal hearing and I used to be a cost clerk. And I knew that I had it in me. I just wanted the initiative, for someone to say, 'We have accepted you with your deafness'."*
>
> Deaf woman, age 61

Public acceptance and personal control

One of the key features in these extracts is the control people are able to take through public acceptance and being able to be themselves in a range of circumstance. For Deaf people, this may mean being able to be Deaf in groups of hearing people as well as groups of Deaf people, but in circumstances where their language is acknowledged and their difference accepted. This is not always the case.

> *"In my college years, I had it again, being different, but I coped. It was difficult to lipread, and I got written notes, and had to do extra work at lunchtime. I developed an acceptance of the difficulty, but it wasn't easy ..."*
>
> Deaf woman, age 40

> *"... all of a sudden, they mentioned my name. I realised I had won something, but I didn't know what, because I hadn't been paying attention! So I asked what it was about and someone told me that it was for being a good signer. I realised then and felt embarrassed, but at the same time, I was really pleased and felt proud".*
>
> Deaf Asian man, age 25

The discovery of language is an important part of creating a public identity and of being able to seek explanation and knowledge. However, there is a perception of deafness as a public 'spectacle', particularly with regard to the use of sign language (which is, ironically, at variance with the notion of deafness as an 'invisible handicap') and this increased public exposure and the perception of public ownership that accompanies it, is seen as a shift in control by several Deaf people.

> *"What first really made an impression on me - it always has done - was the public nature of deafness, all in the public gaze, for all to see."*
>
> Hearing man, professional, age 41

> *"A lot of my hearing friends can sign now. This means I can't sign in pubs now and be open with my Deaf friends, because lots of hearing people can sign now and they know what we are saying. Before, we could be more open."*
>
> Deaf woman, age 40

> *"Anyway, later when I got to _____ school, it was different from my old school, which was more oral with a bit of sign. I was amazed. It had strong BSL, people's hands moved much bigger. I sign*

in a small area. I was fascinated, and got really interested and started to pick up BSL for the first time. So, I learnt at that school to start to question teachers about deafness... I used to ask a lot of questions, and the teachers always explained." Deaf man, age 25

So, it seems clear that finding out - about deafness, about one's self, about where people can be themselves - and seeking explanations for the denial of their deafness and their exclusion from public inclusion and connection, are central issues in people's accounts. This search for acknowledgement is part of people's struggle to find out who they are and denial of this constitutes a denial of self which people, rightly, challenge.

"The creep hid my file. He told me there wasn't one. I wanted to know about my childhood" [my emphasis] Deaf woman, age 42

Information, control and significant others

So people may be denied access to their different and equal experience and the opportunities to be themselves in a wide range of circumstances and with a wide range of people. This may occur because this experience is not acknowledged and their aspirations to connection and belonging are overlooked, so restricting their opportunities for public inclusion and acceptance. In these circumstances, information is crucial, as is the way in which help is provided and sought and by whom. Central to this whole process is the degree to which deaf people are able to retain and exercise control in their lives.

Information is a complex subject and this is reflected in the way in which people deal with it in their accounts. However, three strands can be discerned from the way people talk about it. Firstly, there is information itself. Clearly, information needs to be full but on its own it has little meaning. Secondly, then, there is access

to information, which is not just about physical access but having the means and the opportunity to obtain the information one wants. And thirdly, there is the use of information and the extent to which people are able to make use of information for themselves and in their own circumstances.

> *"I often received information that went over my head, and it made me feel down. Also, getting <u>oral</u> information makes me angry, it just goes over my head ..."* Deaf man, age 28

> *"No one understands or realises that we need that information... I see a lot of Deaf people frightened to ask for information at the Deaf club. It's important to tell all Deaf people where the Deaf club is, so that this information can be handed out. You see, the Deaf club has its own voices and access. It's not fair that some Deaf people have poor education, and they need explanations from Deaf voices ..."* Deaf woman, age 42

> *"I'd like to see more TV programmes about <u>our</u> culture, our way of life. Because I'm deaf, there's a lot I don't pick up. We need our own interpreters. The only way to get information, really, is from Asian Deaf people ..."* Deaf Asian woman, age 19

> *"It [the video phone] would eliminate deaf people's problems who rely on BSL as a first language. Their problems would be gone on the telephone, but their 'problems' would still not be gone, because they have to participate - they don't <u>have</u> to - but they are people, and if they want the best out of society, they've got to participate to some extent. They can't do it on their own, but they can't participate because they can't understand. Everything's going on, and they can't get enough information, they can't understand the information they get, sometimes, so it gets more complex ..."* Deaf man, professional, age 32

Professionals seem to recognise the overriding importance of information to deaf people, yet seem almost overwhelmed by it themselves. This may be connected with the very close relationship between information, third party helpers and control. Professionals' confusion about information may well reflect their confusion about the control that *they* are exercising in deaf people's lives through the way in which they provide or give access to information. Deaf people seem to have a much closer appreciation of this.

"In some respects, I'm not sure whether they want that [all information on video]. I think it's a right in many ways. I think it should be there, that there is so much other information, some of it useless, that's around for the vast majority of people. A quick scan at it, and you just throw it away. No doubt it is of use to someone at some particular point in their life. So it is available. But you don't have that for the deaf, so if you had this wide range of videos, they don't have to be used, but they are there as a source of information that people can turn to when they need it." Hearing man, professional, age 38

"I think we have a, well, I hold the belief anyway, that if we applied sufficient effort, which I think we will do, to consulting with specialist organisations, seeking their agreement to circulate information on the community care plan for instance, to people who are registered deaf or hard of hearing, known to all specialist organisations, using public libraries, using public notice boards in centres of population, together with specialist agencies, either local organisations or nationally, we should be capable of, as they say, meaningful consultation. It is a direct relationship on energy, good advice and application."
Hearing man, professional, age 45

For deaf people, the relationship between control, information and the third party is part of their experience and it is this direct experience that clarifies issues of dependence, help, rights and control for them.

"Some information can be quite upsetting, so I was only told a little. My mother got upset when she was giving me information from the doctor... It was years later, when I asked to see a different doctor in London, that I was given a great deal of information. I started to get to know about the problem, then I looked into a book about health, for more information. No one explained things to me for a long time; I got no advice. What happens when my mother's gone? You see, I've got a right to know ..." Deaf woman, with retinitus pigmentosa, age 52

"My first reaction was to go to the library and I sat outside in the car because I was too frightened to go in and read about it [Meniere's Disease]. I sent my husband in, and he found out." Deaf woman, age 51

"With respect to issues concerning deafness, yes, I felt quite confident that I can eventually get the information somehow, and know about how to get it. I'm happy with that. If it was information, for instance, as a social worker, if it was genetic information that society, other people, need to have to get, I have a more difficult job as a Deaf person getting this information, because I'm deaf. I cannot hit the phone and ring round people's offices to get this information because they haven't got a minicom. In the same way, I find it easier to jump into the car and

go to somebody's office and have a chat with them, rather than speak to a third person ..." Deaf man, Professional, age 32

The Third Party and the mediating relationship

These extracts suggest how important third persons are for deaf people. It is clear from the accounts of participants in all three groups that third parties play a key part in people's experience of deafness. For deaf people, they are often the mediators of contact between themselves and hearing people and are also significant sources of information, support, protection, guidance, help, friendship. In fact, they cover the whole range of ways that any of us use third parties. What makes deaf people's experience of them different, though, is that very often a single person fulfils the whole range of functions, there are very few of them in people's lives and deaf people have very little control over what they do.

People's accounts of the help they want and receive and who they want to provide it, show that issues about the third party and the mediation relationship in which help is provided are enormously complex and very little understood. This study did not specifically look at how people use help and helpers but recognised that this was an important area of people's experience and gave them opportunities to talk about it. They did. People talked about how good social workers were, how bad they were, how much they trusted them, how much they did not, about using members of their family as interpreters in 'private' matters such as health, about using interpreters in the same circumstances, about how distant and removed doctors were, about how good hearing therapists were, about how helpful doctors were, about how good neighbours were, about how bad neighbours were. And so on.

It is not possible for me to unravel all the complexities in the mediation

relationship and the role of the third party here. As I have said, its complexities are very little understood. Yet the third party and the mediation relationship remains the model for social welfare services for deaf people in the UK. There is clearly a need for more, and urgent, research in this area. However, people's accounts do highlight a number of key issues that I can set out here, which I believe are crucial to beginning to understand the nature of this role and relationship.

Dependence, trust and control

There are issues about dependence, to which many people refer; about trust and control; and about the way that third parties and the mediation relationship, promote and restrict people's aspirations to connect with others and enter into reciprocal relationships that can give them power and equality. This seems to set up the third party as either connector or separator. Traditionally, the third party - whether welfare officer, missioner, social worker, teacher, interpreter, communicator - is seen and promoted as a connector, a provider of access and information.

> *"... but also, when I am giving lectures or talks about the deaf, I always say I am the bridge between the two worlds, that the knowledge I gain from mixing with hearing people, I think I can enrich the deaf, by bringing that knowledge and information to them, because otherwise they will miss it."* Hearing woman, former professional, age 61

The notion of the third party as a bridge is a fairly common one. it is often used to describe the *role* of the third party, by hearing professionals. Interestingly, when I looked in people's accounts for references to it, I only found two, both by hearing professionals. One of the major problems about the notion is that it implies that the third party is a neutral conduit and does not acknowledge the relationship and process in which the third party is involved.

As a consequence, others in this relationship and process, particularly deaf people, are denied the opportunity to think about the issues of control and power that are contained in them or to exercise them.

This seems to be quite crucial. What comes across fairly clearly in people's accounts is that deaf people do not think about roles or the defined functions of the various different third parties and this is one of the main reasons why their references to them are so varied and, often, contradictory. People tend to think of help in terms of what they want and how it happens. They seem to understand the processes and relationships more clearly than professionals and this is most probably because they are living them.

> *"Subtitles help us know what's going on. Otherwise, everything would be going over our heads. People who hear are lucky. They can hear things, like about financial crises, or economic policy, and all the other news every day. They know before us."* Deaf man, age 25

> *"It's the hearers' problem. They should come to help us because they listen before us, see? We deaf people have to wait because they have all the information which they can talk to us about, but they haven't got the courage to tell us, do you see ?"* Deafened man, age 51

People understand this sense of dependence and the effect it has on them. It is a central feature in the role of the third party and the mediation relationship and in our understanding of help, helping and helpers.

> *"But, you know, I hate lip-reading classes and I don't like Monday night [her signing class] because you are reminded all the time, every Wednesday, when we went to the lipreading classes. And Ann said, 'Don't you enjoy it, Mary?' And I said I didn't, really, and she asked why, and I said, 'Because I need it.' It's the only answer I could give her."* Deafened woman, age 62

> *"As a baby, well, no one would remember that far back, but I do remember seeing the family talking and talking, and knowing then that I was different. I relied on my younger brother, and followed him around. He was my eyes. When he was happy, I smiled, knowing everything was OK, but when he was sad I knew something was wrong.*

We would hide, and I would just follow him ..." Deaf woman, age 42

Active and passive dependence

These extracts seem to show different perceptions of dependence, which arise partly from not being able to hear but also from people's different attitudes towards the ways they need to act in order to take control in these circumstances. For Deaf people, the third party - whether younger brother, friend, neighbour, work colleague - is the means by which they address the separation and restriction imposed on them by the lack of public acknowledgement of their deafness and their Deaf identity. Their reality is that they are cut off and denied access and they seek third parties as their positive action to address the exclusion.

As a consequence, they seek particular people to help with particular things such as neighbours to help with the telephone, or members of the family to accompany them to the doctor, or social workers to help negotiate with public utilities. They are *actively* dependent on third parties and are trying to exercise control in the mediation relationship.

For deafened people, this dependence may be more passive. Their reality is that they have been excluded from a world in which they used to live and are constantly having to struggle with not hearing. For them, the third party may temporarily relieve this struggle.

"I'm still very uptight about it, but if I sense in somebody, and they realise, and they try to be helpful, then it is wonderful".
Deafened woman, age 50

"They must meet the right person to communicate with them, to explain to them". Deafened man, age 51

It may be that we do not understand this difference in dependence, and assume that

deaf people's dependence is only *passive*. The third party then becomes the person in control and the limited number of people in this role becomes a crucial factor in further isolating deaf people from others. This restricted, passive dependence then becomes institutionalised into the attitudes and practices of professionals and the service structures within which they work. Deaf people's needs are seen *in terms of* a small number of people who exercise the control that deaf people cannot, rather than in terms of the control that deaf people want to exercise to deal with the restrictions imposed on them by public denial of their deafness.

> *"They have actually said that they like a few people that they can approach. It was interesting, because after I left _____, not a profoundly deaf, but almost profoundly deaf client went to enormous lengths to contact me to ask my advice about something, because he trusted me. I was the one out of the many people in his area that understood him. So. I think deaf people want a few people who can understand, who they can trust, not too many people... I feel, personally, that it is restricting,and there should be more, but I think, personally, often themselves they are a bit nervous and anxious about it."*
>
> Hearing woman, professional, age 35

> *"I think if you included the question of interpreters, the question of some kind of central figure to which a deaf person could go and say, 'I have a complaint about such and such', and that person would be able to deal with it independently, of a social worker, or anybody else. I think that would be very important if the deaf knew there is a person that they can go to and get satisfaction".*
>
> Hearing man, former professional, age 66

This denial of people's control, which the notion of passive dependence creates, seems central to our understanding of people's different perspectives on help and helpers. Deaf people, especially those who are culturally Deaf, challenge this denial and the notion on which it is based, by questioning the structure of services that derives from it.

> *"It's better to separate the roles of interpreter and social worker, because the social worker has not got enough time to cover everything".*
>
> Deaf woman, age 46

"Social workers and interpreters are good around here. But, sometimes I don't know which one to have. I'm often told that I should have <u>this</u> person, rather than the social worker. Usually, I want that person, not the other. I often disagree, and say I want the person who is the social worker, and deaf. I often ask for that person to help me... Also, the other person often tells me what to do, that one job is better than another, for my future. I don't like that. I prefer to make my own decisions about work."

Deaf man, age 26

"I'd like to talk about social workers. I wrote to them ... and asked why they couldn't come with me as an interpreter. They wanted me to get one from outside. Why? I asked them to come with me as an interpreter, but the reply was that it wasn't allowed, that I had to get one from outside... I think I object to that. Those social workers are there to work for us."

Deaf man, age 52

Professionals clearly experience difficulty in administering this service structure. This is not really surprising. They are working to create opportunities for deaf people to exercise control in their lives and to address the restrictions imposed on them. Yet they are having to do this with a model of service which uses single third parties as the main provider and is based on notions of passive dependence which assume that deaf people are unable to exercise control over the restrictions in their lives and this control has passed to the third party. Professionals are trying to empower people with disempowering mechanisms.

People talk a great deal about trust in relation to help and helpers. This can be seen in terms of the extent to which Deaf people trust others to allow them to be actively dependent in the

mediating relationship, being able, in other words, to exercise some control.

"I hope the social work services are better now. I've started to trust one now, but not before ... most social workers were not honest, and it put me in doubt ..."

Deaf woman, age 44

"I like to have an interpreter, because it's private and confidential. Using family, they can be nosey ..."

Deaf man, age 61

"Mostly, I use my mother to interpret, because, you see, I feel you

cannot trust the interpreter ..." Deaf woman, age 50

So, the issue of trust is not primarily about social workers, interpreters, communicators, relatives, friends, but about people's sense of confidence and safety in their active dependence. Deaf people do acknowledge this active dependence but also aspire to connection and independent action as means of exercising control in their lives.

"We deaf people here are campaigning for interpreters ... we want to have good interpreters, and not have to use parents or family. I am an adult now, so I don't want to have to use my family... We also campaign for the police to provide interpreters. They also now have a minicom at the police station. It's nice to know that I'm able to ring the police by minicom, so that they come round, or send fireman here, or an ambulance, if I need it. I don't have to ask hearing people any more. Now I can lead my own life. " Deaf man, age 62

"Actually, its better to do things for yourself. It gives me more experience of thinking, of how to do things, of the future, of how to solve things for myself. There's no point in being heavily involved with a social worker, I'll never learn that way. I'm 25 now, and it embarrasses me, you see. I know that social workers are about the same age as me, and I feel ashamed that I can't do things for myself. It my future. This is important for deaf people." Deaf Asian man, age 25

Moral power and reciprocity

It does not seem, therefore, to be the third party - whoever this is - or the mediating relationships itself which restricts deaf people's aspiration to control their own lives and which deaf people challenge, but the lack of acknowledgement of imbalances of power and control that exists within this role and this relationship. These imbalances seem to arise when people are denied opportunities to exercise their moral power, which is their ability to assert their sense of who they are.

This ability can be seen to derive as much from people being able to be actively dependent and to access the control that this gives them with the third party in

mediating relationships in these circumstances, as being able to act independently. It is restricted by the imposition of passive dependence, which moves control from the deaf person to the third party, who may then exercise it - and moral power - on their behalf.

I describe moral power as being neither quantitative nor qualitative. No one person has more moral power than another, and no one person's is better than another's. Each person has sufficient to assert their identity, in whatever circumstances they are in. Here are some examples.

A friend described to me how her nephew, who was six and whose birthday falls just after Christmas, told her, in front of her horrified stepson, that he really had received enough presents for Christmas and there was no need to give him any more for his birthday.

A woman purses a complaint of sexual harassment against a powerful male manager at work, notwithstanding the personal, social and emotional pressures this puts on her.

There seem to be a number of features to these assertions of idenity. One is 'I count' and 'I matter'. This seems to be the acknowledgement of the private self. A second is 'I count in relation to others.' This is a more public acknowledgement of self and a recognition that others' actions affect self and self's actions affect others. A third is 'I recognise that others count as well', which is the recognition that what we do we do not only on behalf of ourselves but also on behalf of others.

So, people's moral power is exerted in a social context and is equivalent. However, what differs for many marginalised and oppressed groups, including deaf people, is the range of opportunities in which they can exercise it.

The development of moral power arises from people's opportunities to engage in reciprocal relationships with others, which permit people to be themselves in circumstances of fairness and equality. Deaf people seek these relationships, in just the same way as anyone else and value them for the same kind of reasons.

> *"Yes next door, he could hear for me. My next door neighbour is really good to me, we're good to each other... When he has a problem, he comes and asks, say, if I've got anything to do decorating with, with, so I lend him paint brushes, rollers, papering table. And I'll do the same. I'll be honest with you, if I'm broke, or have no money for bread or milk, I ask next door, and he lets me have some ..."*
>
> Deaf man, age 52

> *"... I just enjoy it [her job as a home care assistant]. I think that elderly people are very interesting anyway, because they have lived longer and they have all of them, without exception, got tales to tell you, which is very interesting, about their life. And I just enjoy doing it, and I just feel that it is worthwhile. It is a worthwhile thing to do, because you are helping them, and I just enjoy doing it ... there again, it is a reciprocal thing. I am helping them and they are helping me, by making me think, well, then I am doing something which is worth while ..."*
>
> Deafened woman, age 61

I believe that passive dependence arises, and is imposed, in circumstances where people are denied the chance to enter into reciprocal relationships and connections with others, where they are only receiving - help, information, guidance, support, protection - and not giving as well.

Becker (1986) considers the development of moral attitudes and behaviour as a basic element in people's ability to engage with each other in a free and equal society. He focuses on the way that such moral attitudes are developed from and exercised through reciprocal relationships. He identifies three important features to reciprocity. Firstly, there is *exchange*. In any relationship, one person gives a good and the other gives back. Secondly, there is *equivalence*. The returned good is what the first person might want to receive, rather than what the other person wants to give

back. Thirdly, there is *active choice*. People are able to both give *and* receive. In this way, people can engage, as themselves, in equal relationships where they are empowered.

So, what happens when people are unable or are prevented from entering into reciprocal relationships? People lose power and equality and can then be perceived as helpless and vulnerable, opening the way to the assumption of their passive dependence on others, who then exercise power on their behalf. In the case of deaf people, it is often third parties who exercise this power and who have control in mediating relationships.

This, as I suggested earlier, may well create difficulties for professionals as well as deaf people. They do not seek to exercise power in this way, yet are forced to by the role they are in and the service structure that supports it. They may also find it more difficult to challenge than deaf people do partly because by exercising moral power on others' behalf, they are denied access to opportunities to exercise their own.

By revealing the inequalities in relationships, power and control and the different ways people exercise it and seeking to understand these better, it may become possible for us to redress the imbalance of control, which deaf people challenge, and create more empowering relationships for them and us. This is likely only to occur in equal exchanges between deaf people and others, where deaf people's different experiences and perspectives are acknowledged and valued.

Social justice demands that we acknowledge deaf people's experience, place them in the same continuum of opportunity as ourselves, seek commonalities of experience with them and create the circumstances for people to empower themselves.

This will mean questioning not only the meanings we have constructed about deafness, but also the nature of the service structures set up to redress restrictions in deaf people's lives, as these may not enable us or them to do this. This will mean addressing deaf people's needs and aspirations in terms of the human rights they share with us, rather than just the deafness that they do not.

CHAPTER 9

FINDINGS AND IMPLICATIONS

This thesis has been written in two parts, one describing the process through which it took place and the other making a commentary from the evidence of people's accounts to show how questions posed by the research can be addressed. These two elements of the research are linked, the one enabling the other to happen and in such a way as to stay faithful to the principles on which the research was founded. The research sought **to provide knowledge** in an area beset by expectations and partial perspectives; **to create acknowledgement** of the understandings and experience of deaf people; and **to be empowering** of deaf people. My discussion of outcomes takes place within the context of these intentions.

In this chapter, I present a consideration of the key findings of the research, both in relation to the process - the methodology - and to the outcome of this process - the commentary.

There are three aspects to the context within which I conduct this consideration.

Firstly, there is an **aspect of principles,** which I deployed to the conduct of the research in order to provide knowledge, create acknowledgement and to be empowering.

Secondly, there is a **personal aspect,** from which I addressed three questions about my professional experience as a service provider to deaf people in order to use my developing understanding of my oppression of deaf people to understand the nature of theirs by others:

- Why is there always a gap between what I offer as a social worker and what deaf people want and need?
- Why are deaf people not able to articulate their needs and wants?
- Why does there always seem to be a tension between what I think deaf people need, what my employers are prepared to offer and what deaf people want?

These questions related to the apparent failure of the present model of service provision to meet the needs of deaf people, those of the professionals who provided these services and those of the people given the responsibility to develop these services within the social welfare structure. One of the key outcomes from the research is that consideration of these questions needs to focus on the nature of the relationship between deaf people, hearing people and the third parties who mediate contact between them - a relationship that we may not understand as well as we assume we do.

Thirdly, there is an **academic aspect**, which is bound by the research questions I posed;

- How do different groups of people understand the experience of people who are deaf?
- How might differences or similarities arise?
- What effect might any differences or similarities have on the way deaf people are given or receive services?

My discussion of outcomes centres on two issues; the *value of the methodology* in terms of its influence on the outcomes and the *value of the commentary* in terms of revealing insights and adding to knowledge.

The methodology I have chosen has enabled me to elicit from participants accounts that are rich, complex, diverse and dense - and I have created both diffi-

culties and opportunities for myself by doing this. In the first instance, I cannot provide the kind of full and detailed answers to my research questions as I and others might have wished. This was never my explicit intention but it has remained a powerful, implicit expectation throughout the research. This can make me defensive about the outcomes of the research and this defensiveness has sometimes blocked me off from different and perfectly valid ways of presenting these outcomes - and sometimes from seeing the outcomes at all. Furthermore, the complexity of the issues that are revealed by using this methodology means that my explanations may necessarily be complex and dense. This makes demands on the reader but also makes a demand on me to set out these issues in as clear and open a manner as I can. This is not always easy and at times I may retreat into the sanctuary of obscurity.

So, here are the key findings in relation to the impact of the methodology.

'The methodology has created a central organising mechanism for the research'

The methodology has allowed me to develop and retain the central principles of social justice and equality that I felt were essential to any investigation of notions of oppression. It produces rich, complex and insightful accounts which reveal new questions, issues and relationships. This richness and complexity might well be attainable using other methods, such as semi-structured interviews, but I would contend that by introducing more structure these methods may risk undermining the principles of equality and social justice by being more impositional on people in terms of what they are permitted to say and how they can say it. Maintaining an equality between the evidence of people from different groups and with different experiences has been

an important outcome. I will be discussing this further later in the chapter.

'The methodology reveals new insights'

In the first instance there is a general issue to consider. The methodology has created, through the framework and the commentary, a channel for revealing new questions, new relationships between people or issues and new ways of looking at existing relationships. This revelatory aspect is vitally important. It addresses questions about knowledge, about the nature of relationships between different groups of people and about their perceptions of deafness and the experience of deaf people.

The commentary reveals that people use a variety of sources to help them understand their own experience such as those of their culture, class or gender. It also shows how people can be cut off from these experiences and denied access to them as a source of understanding and acknowledgement. It is clear that professionals in particular may be struggling to understand the experience of different groups of deaf people because they are only given deafness as the experience with which to understand this - an experience that they, in the main, do not share.

There is an important implication here about knowledge. Practitioners, especially those in close working relationships with Deaf people, are a primary source of information for policy makers and advisors. What are these practitioners *expected* to know - and are they able to say that they do *not*?

'Personal accounts are a valuable resource in developing knowledge about deafness'

There are two aspects to this finding.

Firstly, it is clear from the commentary that personal accounts provide *a rich source of understanding* both for the people whose accounts they are and for those who listen to them.

Secondly, using a common form of interview in the research provided the opportunity for each participant to give their account in circumstances of equality. This equality means that we can give *value to different perspectives* - and the variety of experiences that comprise them - which allows us to look at traditional relationships and adopted understandings in new and revealing ways.

The research sought to understand more about the ways that people are and are not able to articulate their wants and needs and to broaden the base of knowledge about deafness by revealing the understandings of deaf people and those of professionals who work with them.

The commentary shows how people have often not been given the opportunity to explore or understand their experience. For deaf people, this denial is often part of the service structure that is trying to help them. For professionals, it is the lack of opportunity to connect different aspects of their experience. For both, this may centre difficulties in accessing or providing services on individuals and promote private and personal, rather than public and corporate, responsibility for challenge and change.

There seem to be important implications here for professional development in terms of enabling professionals to acknowledge the variety of sources available to them to understand the experience of deaf people. It is clear that professionals lack opportunities for reflection and this may well be having an influence on the effectiveness of their practice and their ability to acknowledge the validity and meaning of deaf people's experience.

There are also implications for ways in which deaf people can be involved in assessments of their needs. Assessments, whether formal ones for access to services provided by community care or informal ones that form the basis for advice on policy formation and development, need to acknowledge the experiences of deaf people and the ways *they* understand these if they are to be effective and equitable.

Autobiography has great importance. As Giddens (1991) suggests, it provides the anchors, framework and certainties that individuals need to place themselves in the world. In some ways it may, in a modern world, replace the anchors and certainties that Giddens suggests were relatively fixed in pre-modern societies in Europe - lineage, gender roles, social status. It is important, though, for us to understand that these fixed relationships have not disappear without trace as people moved from a medieval to a modern society and that these relationships may still be strongly institutionalised in the structures of our lives. For deaf people, these fixed relationships may be more embedded in their lives than in those of others, through the meanings of their experience imposed on them by others or by the mediating relationship which governs their contact and connection with others. This may restrict their ability to form their own autobiographies in order to regulate their place in the world and may also restrict the ability of others to understand their autobiographies when they try to deliver them.

It seems possible as well, and our reality seems to support this, that we use a combination of individual and institutionalised anchors to create our sense of who we are. What happens, then, if these anchors are overshadowed by a single defining experience, especially if this is defined or imposed on us by others? We may then be unable to use other sources of our experience - our gender, our class, our culture -

because they do not fit with the defined experience. We may then be denied our ability to present and create our own autobiographies because these do not fit with the understanding of deafness that has been created by others.

It is clear from people's accounts that the methodology has enabled people not only to create and present their own autobiographies but also that these autobiographies themselves can form an important part in the development of services.

'Independence is an important feature for investigators and participants'

It is clear that investigators who are independent of service-providing structures have an important influence on the outcomes of the research and in particular on the ability of investigators to elicit, and participants to give, meaningful personal accounts.

There are a number of features to this. Participants clearly respond to people with whom they can identify in some way, either because they share the same experience or because there is a shared understanding of the experience at some level. For professionals, this may be the shared professional experience or the perception of this; for deafened people it may be the perception of some previous experience of working with deafened people; for Deaf people it may be the shared use of a language or a cultural experience; for researchers it may be the sharing of a learning experience. For all, however, it seems to be connected to the acknowledgement of a shared *human* experience, the willingness to acknowledge another's experience.

As a consequence, people were able to move from public to private accounts and in the process were able to construct their own story from a variety of texts and provide a rich source for developing new understandings and insights.

There are implications here for user involvement structures and for advocacy

and representation. These centre on the type of methods used to elicit information about people's views and perspectives and the people involved in obtaining these views.

These are the findings that have arisen from the commentary:

'Challenge is a central issue for deaf people and for professionals'

It is clear that deaf people do not accept the limitations imposed on them by meanings of their experience created by others. This challenge may take a number of different forms, from direct challenges to professionals and services to seeking ways of living and behaving that correspond to people's own image of themselves rather than that imposed on them by others.

Equally, professionals may wish to challenge their sense of powerlessness but may be denied a suitable range of opportunities to do this. Their challenges may then be focused in the experience of deaf people where they seek to understand their own sense of powerlessness only in terms of deaf people's. This cannot provide them with a satisfactory explanation and deflects their challenge away from existing oppressive institutions or ways of working and therefore, by default, sustaining them.

There are implications here for social work practice, especially for the ways we deal with other people's anger - and our own.

There is also a clear need for further research into notions of active dependence and passive independence; the development and deployment of moral power; and our understanding of how deaf people can establish reciprocal relationships and what may prevent them from doing this.

'There is a connection between gender and deafness'

There are clear indications in people's accounts that this is an issue and it is one that has been identified by other recent research (Gregory *et al*, 1995). However, it is a connection which remains largely hidden, both in the way that research deals with it and in the way that people seem to be able - or unable - to talk about it.

There is a clear need for more and urgent, research about this connection and, from people's accounts and the commentary I have made from them, there seem to be two aspects to it:

- the way that women may be denied access to their gender experiences by the dominance of deafness as a defining experience, which restricts their ability to create their own autobiographies and texts, in much the same way that Deaf people use their Deaf experience to create theirs;
- that there may be a difference between the way men and women experience deafness. This may well be connected to the prevalence of high tone deafness and the implications this has for people's ability to hear men's and women's voices.

However, I detect another possible source of difference and this relates to men's and women's routes to independence and the different ways that they experience being alone.

'There are different ways of being deaf and becoming deaf'

Our notions of what it means to become deaf and to be deaf are challenged by the experience of both Deaf and deafened people as they describe it in their accounts. It is clear that these are both processes which are continuous and through which Deaf

and deafened people understand and develop their sense of identity and their relationship with others. Hearing people's notions of these processes often impose restrictions on deaf people's ability to do this.

There would seem to be major implications here for the way that social welfare professionals make assessments of people's experience and therefore of their needs and wants. An assessment based on the assumption that people become deaf once, for example, denies the many difficulties and restrictions created for deaf people by the attitudes and behaviour of non-deaf people which makes them deaf over and over and over again. Similarly, an assessment which assumes a single way of being deaf, one, for example, which denies the importance of a person's hearing experience, restricts the ability of people to discover their own sense of who they are.

'Fear is a central part of people's experience of deafness'

I believe this is a large issue. It is also one which is difficult to write about as it is often denied. It centres on hearing people's fear of deafness and not on deaf people's fear and this may be one of the reasons why it is so difficult to unravel.

Potentially, it has enormous implications for the way in which services deal with deafness and with people who are deaf. One example of this could well be the continuing difficulty that seems to exist in the identification and diagnosis of deafness in children. This has been a primary target area for change, by both voluntary and statutory agencies, for a number of years yet it is clear that parents and families are still experiencing difficulties in having their child's deafness acknowledged.

'The mediating relationship is central to the understanding of the experience of deaf people'

We do not understand the mediating relationship. Deaf people seem to have larger areas of their experience mediated through third parties, both as a result of their deafness and their use of a different language, than might be the case for other groups of people. This means their opportunities for direct experience, through which they can build up their picture of the world, their place in it and their relationships with others are limited. This is clearly *not* something that deaf people seek. Indeed, it is one of the main restrictions that they challenge.

There are many aspects to the mediating relationship and understanding it through the experience of those who live it gives us a different perspective on it and can lead policy makers and service providers to a different way of constructing services in relation to it. I will explore some of these in my discussion of the next finding.

'Third parties play a key part in people's experience of deafness'

This is connected to the mediating relationship. It is clear that the mediating relationship is defined on the one hand by the people who act as third parties and it is largely professionals who define the relationship in this way, and on the other by Deaf and deafened people, who see it in terms of what they want and need from it rather than what third parties can or do provide. This creates an area of conflict and challenge.

This conflict seems to be connected with one of the possible origins of the model for this relationship. Whatever third parties do, whether they interpret, act as social workers, advocates, supporters or friends, they seem to be constrained by the

same role limitations. This suggests that it is the model itself which is causing the difficulties.

The model for the helping or mediating relationship between hearing and deaf people seems to be one that encourages passive dependence, which takes as given the *permanent* disadvantage that deaf people have in relation to others who hear and in a hearing world and where the third party has great power, which is rarely acknowledged by any of the parties. It is also a relationship that is characterised by feelings of powerlessness in the third party.

The relationship may have as a model that of deaf parents and their hearing children. We might explain the nature of active and passive dependence in terms of this relationship, where the parent is often dependent on the child, even though this dependence is not sought by the parent. The sense of powerlessness of the third party can also be seen in relation to the power exercised by the dependent child, who may not seek this power. This relationship exists in a context of social expectation, where society expects 'the family' to care for its dependent members and where society has constructed the notion of deafness as a dependent state in the first place.

'It is as important to emphasise similarity as difference'

What does acknowledging different ways of understanding mean? From our acknowledgement of the equal value of different perspectives we can take an existing relationship and look at it in a different way. Our understanding of the mediating relationship, for example, is largely based in its form; that is, the way that it works, and particularly the way it works from the perspective of a particular, dominant group in the relationship. Traditional understandings may identify this group as hearing

people. Valuing and listening to different perspectives and giving equal weight to difference and similarity present us with other ways of understanding this group and the origins of their perspective - and of understanding the nature of the mediating relationship.

So we can, for example, locate our understanding of the mediating relationship in the *ordinary* relationship between hearing children and their deaf parents but one which may be made *extraordinary* by the expectations and imposed meanings of society. In order to understand this relationship fully - and to understand the ways that it seems to *succeed for and fail* the different people involved in it - we can now see it as a relationship which exists between three groups or interests, each with their own perspective and where society and social structures are important and influential players. These perspectives and interests define the way the relationship is seen, in terms of dependence and independence, in terms of control and power, in terms of usefulness and in terms of equality and social justice.

This means we can now start to understand that the relationship may fail not because of the failings of professionals, or mediators, or deaf people but because the expectations of a social welfare structure that demands it fulfil functions for which it was not designed. After all, the relationship between hearing children and their deaf parents is not unique. Similar aspects exist in relationships between children and their disabled parents and between children and their non-English speaking parents. The meaning of these aspects is defined not only by the nature of the family relationship but also, crucially, by the expectations and demands of a dominant political and social ideology.

'Addressing the oppression of deaf people is a corporate responsibility, and not just a personal one'

This is the finding that has probably the greatest personal significance for me but also has potentially the greatest impact for the development of services and service structures to enable deaf people achieve a greater measure of equality and inclusion.

Traditionally, this kind of help has been offered through a small number of individuals who are only marginally connected to the mainstream of social and political development.

There is evidence in people's accounts of an increasing wish and willingness of people to seek ways of redressing inequalities and disadvantage through collaboration and contact with others. This has been, of course, a feature of Deaf people's cultural experience for many years. It does seem, though, that people are wishing to make wider collaborations, both to address their own individual disadvantage as deaf people and also to seek, as policy makers and service providers, new ways of understanding the experience and perspective of deaf people, and their place in society.

CHAPTER 10

ENDING

This is the third ending I have written to this thesis. The first was imposed on me - quite voluntarily - and enabled me to complete my research. The second was mine, written at that time when I sought an ending for myself. This third enables me to combine these two and is partly the result of my taking the findings into my continuing working life, and applying them. I now know they work for me and for others, and this makes me more confident about my findings and my ability to explain them to others.

This thesis is now ended. Yet it is incomplete. The framework for understanding that it describes, which derives directly from people's accounts of their experience of deafness, has set out a large array of parameters and issues that deserve elaboration. This commentary has not addressed all of these and could have explored the ones it has in greater depth. It does not need to do this and, in one important sense, it must not. To attempt to do so would be to seek universal resolution and this cannot be. Principles of social justice require that no one person or group of people should be able to resolve all uncertainties and answer all questions. Uncertainties and questions must remain, even though I may need, in a modern world, the reassurance of certainties and answers. This enables others to pick them up and move them on. *My* uncertainties and questions are not necessarily those of others so I must release mine and continue to say "I don't know", in order to allow others to say, "but I do".

This type of framework and the parameters that form it is open, inclusive and

capable of transformation. This means that each new issue and new experience can change the framework and transform the commentary to include different people's experience at different times. I hope that it allows people to bring their experiences to it and to change it in the light of them, so acknowledging their identity and perspective and releasing **their** power to promote them.

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APPENDIX 1

Review of Social Research Studies on Deafness

This paper is about the method of the study. It reviews five research studies and constructs an analytic framework to identify issues and variables for inclusion or exclusion.

Five studies have been looked at:

A	**Interview with young Deaf school leavers in Inner London.**	Paul Redfern unpublished Masters thesis, 1983.
B	**Social and Vocational Aspects of Acquired Hearing Loss (Bristol)**	Jim Kyle and Peter Wood, School of Education, Research Unit, University of Bristol, 1983.
C	**Deaf People and the Deaf Community (Bristol and Birmingham)**	Jim Kyle and Lorna Allsop, School of Education, Research Unit, University of Bristol, undated.
D	**Public Attitudes in Deafness (National)**	Clare Bunting, OPCS, 1981.
E	**Deaf People Speaking (Highlands and Islands)**	Steven Pennington and Mary Henderson, University of Dundee, Scottish Office, 1982.

These studies were chosen as they look at social, vocational and community experience of Deaf and previously hearing people; they review previous studies in these areas; they provide examples of studies in different geographical areas; they describe different ways of asking people questions.

I have identified ten issues from these studies. I will outline them and show how each issue is treated by these studies. I will indicate where issues are excluded and whether this is by design or by omission.

The issues are:

Gender		A	B	C	D	E
Age		A	B	C	D	E
Race		A				
Class			B	C		
Selection of participants		A	B	C		E
Communication and use of language		A	B	C	D	E
Sample size		A	B	C	D	E
Conducting interviews:	individual	A	B	C	D	E
	group					
Format for interview / study		A		C		
Recording information		A		C		E

Gender

This heading looks at the sex of participants in each of the studies, how proportions were set up and how these relate to national and local hearing populations and to proportions in other studies of *Deaf people*. It also considers gender issues and whether the studies make attempts to describe the impact of these issues, particularly in relation to use of language and the acknowledgement of different types of experience.

Studies B and C report percentages of participants that correspond to local census information and emphasise the importance of having these percentages in the sample. Study A supports this view. Study D did not include sex of participants as a stated variable.

Study	How proportion set up	National / local comparison	Comparison other studies
A	Design	No	No
B	Random	Yes	Yes (6)
C	Random	Yes	Yes (1)
D	N/A	N/A	N/A
E	Random	Yes	Yes

In relation to gender issues, study B (which looked specifically at employment) mentions a percentage of respondents who were housewives but does not include this in the table of different occupations. More specifically, in the group discussions set up in study C, membership of groups was set up according to age but the gender of participants was not thought to be significant and there is no discussion on the possible impact of mixed group discussion on the content or on the type of language used.

None of the studies considers differences in experience between men and women in relation to the issues they address.

Study E found significant difference in the ratio between males and females (3:2 rather than 1:1, and 4:1 in the Highlands). The researcher discusses possible reasons for this.

Age

This study will look at the age of participants and what impact differences in experience related to age may have, and whether studies considered this.

Each study considered a different age group:

Study A	17 - 19
Study B	25 - 55
Study C	16 - 65
Study D	18 - 70+
Study E	15 - 35

Age of participants may well have a significant effect on the type of responses obtained. People who are deaf at particular historical times are likely to have different types of experiences, e.g. born Deaf people in their 50s are more likely to have been to residential schools for the Deaf, than born Deaf people in their 20s who will probably have been to partially hearing units attached to ordinary school. This will have significant effects on the development of sign language and of Deaf identity.

Study C structured group discussions in stage 11 of their research according to age and hearing loss. There is no discussion on why this was done, nor of its effect on responses.

Ethnicity

This heading considers the effect of ethnicity on responses, whether studies include race as a variable and whether studies acknowledge differences in experience arising from ethnicity.

Only one study considers the issue of race explicitly. Study A acknowledges 'race' as a variable but decided against including it in the study as the researcher felt that Deaf young people were more likely to identify strongly with a Deaf culture than with an ethnic culture. This assertion has to be challenged in view of the lack of evidence to support it (the researcher in study A recognises this).

None of the other studies mentions race as a factor. There is no mention of the ethnic make-up of samples and no discussion of the impact of different ethnic experiences on the perceptions and responses of participants. The incidence of deafness in the general population is likely to occur in all ethnic groups equally. There are significant Black and Asian communities in Bristol and Birmingham where two of the studies took place.

Class

This heading is about the different experiences of different socio-economic classes. It looks at whether this factor is considered by the four studies. It introduces the question of whether deafness can be related to class origin.

All four studies look at the occupations of participants. Study A identifies it

as a variable but one that did not influence the selection of the sample. Study C identifies both the occupation of participants and their social class (using traditional social class groupings) and discusses the distribution of Deaf people among various kinds of jobs. Study B, which specifically studied vocational aspects of deafened people's experiences, identifies different occupations and the over- or under-representation of certain classes in their sample.

However, none of the studies considers the effects of class membership, whether defined by occupation or other means, on the types of perceptions that participants have.

It is likely that class origins have an effect on participants' perceptions, whether of their experiences, the research process or of the questions asked of them. These may arise from differences in perceptions of power relationships (employer / employee, husband / wife, hearing / Deaf).

Selection of participants

This heading refers to the means by which participants were selected for inclusion in the studies and in particular the measures of deafness that were used.

Criteria for selection:

Study A (17-19 year old Deaf school leavers)	Hearing loss in excess of 80db over *all* frequencies. Sample source: three schools for the Deaf.
Study B (25-55 year old Deafened people)	Self-assessed in functional terms from questions in interview (using / not using hearing aid) Sample source: registers from social services departments, health authorities and MSC (Disablement Resettlement Office).
Study C (16-65 year old Deaf people)	Self-assessed in functional terms from questions in interview (using / not using hearing aid) Sample source: education authority former pupil associ-

	ations, Deaf clubs, Deaf people.
Study D (18-70 year old hearing people)	Random selection Sample source: electoral register.
Study E 35 year old Deaf people)	Sample source: voluntary agency and local authority (15-register plus social workers and survey of handicapped in Western Isles.

Choice of sample source is obviously determined by what kind of people are to be interviewed. Also, the sources chosen will determine the composition of the final sample.

Selection by using specific criteria of hearing loss, i.e. severity, age of onset, could well produce a contaminated sample. Study A chose 80db as a loss that would probably indicate that participants were using sign language and lip-reading in combination. It is questionable whether this measure would obtain a sample with these circumstances.

It seems important to be clear about all the characteristics of the members of any groups to be studied, and to select sources accordingly. Self-assessed hearing loss may not be an important feature of the sample. A number of study E specifically excluded medical records in ENT departments: a number of reasons were cited for this.

Communication and use of language

This heading refers to communication and use of language by both participants and researchers. It identifies the importance of language in setting the questions and in presenting them and what communication was set up between interviewer and participants and how this was done. It considers the use of language, whether this is BSL or English, and distinguishes this from communication methods such as

writing, speaking (with or without hearing aid), finger-spelling or signing (with or without speaking).

	STUDY				
	A	B	C	D	E
First language of researcher(s)	English	2 English	1 English 1 BSL	English	English
First language of interviewer(s)	English	English	BSL	English	English (with interpreter)
First language of participants	English / BSL(?)	BSL(?)	English	BSL(?)	English
Communication method	Signing & speech	Speech	Signing & speech	Speech	Signing & speech & writing
Researcher(s) Deaf / Hearing	Deaf	1 Hearing 1 Deafened	1 Hearing 1 Deaf	Hearing	Hearing
Interviewer(s) Deaf / Hearing	Deaf	Deafened	Deaf	Hearing	Hearing
Participants Deaf / Hearing	Deaf	Deafened	Deaf	Hearing	Deaf

The question marks against language of participants reflect the difficulty in determining first language use. Study C discusses this in some detail and also looks at how Deaf people themselves in their group discussions defined their language use (in some confusion, in fact). This study also highlights the importance of having a Deaf researcher / interviewer who was both a native BSL user and a Deaf community member, in establishing rapport and in allowing Deaf people to express opinions in their own way.

Study B has a Deafened man as researcher / interviewer with Deafened participants, which again eases the establishment of rapport through a shared social and auditory experience. There is, however, no discussion of the possible difficulties

in communication during interviews that this might create.

Study A looks at the use of language within the interview structure and what affects the use of language in the questions on the understanding of participants. Study C considers the difficulties of translating from English (initial questions) to BSL (interview questions) and then back from BSL (responses) to English (recorded data). I will consider these issues further in subsequent headings.

Sample

This heading relates to the earlier one of selection of participants but also to questions about the size of sample from which participants are drawn, whether the final sample of participants should be representative and what kind of contact method has been used.

Study D highlights the issue that the same depends crucially on the purpose of the study. In this case it was to describe the views of the adult general public without detailed analysis of sub-groups of the population. This meant choosing a relatively small sample size. However, there was intention to make generalised comments from the findings.

Study C attempted to build in the ability to generalise on a national basis by undertaking study of a sample from a different area. The study admits it was not very successful due to difficulties in getting a sample and implicitly because this aspect was added on to the research design.

Study A started with a small sample population and ended with a very small sample of participants (14). It makes it clear that this does allow for generalised statements.

Study A	Letter, followed up by visit to youth club

Study B	Letter and brief questionnaire
Study C	Personal contact and explanation
Study D	Letter
Study E	Letter

Method of contact is obviously very important in relation to the language of participants but also in relation to engaging people in the process of the research. Videos, articles and talks could be used to introduce the project before individual participants are contacted.

Conducting interviews

The heading looks at how interviews were conducted, where they were conducted and considers what influence these might have on people's ability to respond.

Study	How interviews conducted	Where interviews conducted
A	Individual	Participant's home
B	Individual	Research Unit
C	Group / individual + group	Deaf Centre Participant's home
D	Individual	Participant's home
E	Individual (with others present on occasions)	Participant's home + work, Deaf club, university)

The question of using individual or group interviews arises. Study C started by using group interviews in stage 1 but dropped this in favour of individual interviews. There is no explanation of why this was done. This same study used a series of group discussions in stage 2 of its project to provide qualitative information that was non-generalisable. Again, there is no discussion about how this format might

have affected the quality of the information obtained.

The choice of location for interviews may be important. People are more likely to be at their most relaxed in their own surroundings and may therefore be more fulsome in their responses. These may be more difficult to quantify and record. More formal settings may tend to restrict responses to the questions in hand but this may be an over-restriction. Deaf Centres, as centres for socialisation, may be good settings for group interviews, especially when participants may not be well known to each other.

In Study E, a significant number of interviews (50% in stage 2) were conducted with others present (parents, relatives, partners). The researcher discussed the effects of this on responses.

Format for interviews / study

This heading considers the method of investigation chosen by the studies, the way in which questions were presented and explained during interviews and how understandings of questions were obtained and/or measured.

Each study chose a semi-structured interview based on a questionnaire as the method for obtaining information. This relates to the types of information being sought (frequency, distribution, incidents / histories, institutionalised norms and statutes). Other methods of collecting information need to be considered such as personal histories and analysis of documents. These will be considered in later papers.

The studies were all considering characteristics of a certain population in relation to particular issues.

Study A elaborates on the form of the questionnaire that was designed and used, introducing alternative questions if participants were unable to understand the

English form. It was made clear to participants that they should say if they did not understand a question.

Study E used a questionnaire format for the interviews.

As mentioned earlier, study B used a Deafened interviewer but with no reference to ease or difficulty of explanation.

Study C used a Deaf interviewer who translated questions from English to BSL and explanations were presumably offered in BSL. There is no indication (as there is in study A) of what questions required explanation, except in relation to the group discussions where concepts of 'interpreter', 'social worker' and 'sign language' appear to have many different meanings.

Recording information

This heading looks at ways in which information is recorded. The method of recording will depend on the purpose of recording and also on the language in which it is to be recorded.

Study A discusses at length the use of video to record participants' responses. It rejects the use of video because of:

1. need to use two cameras
2. transcription time
3. difficulty in separating interesting information from relevant information
4. because someone else said it was difficult.

Study C used video in the group discussions. This was preset before the warm-up in the discussion and left running without attendance. Quoted responses seem to show that this was very useful and could be seen as a type of personal account. Study B used written responses to questions and to probes, as did study D.

The interviewers in studies A and C tended to record participants' answers

rather than requiring participants to do this.

No study used audio tape recording although study A did consider this, nor a separate note-taker.

Study E used audio tape recording as a note-taking device and for speaking questions and answers from participants. The researcher reports this was successful. Video was not considered.

APPENDIX 2

'Meanings of Deafness' - Research Programme

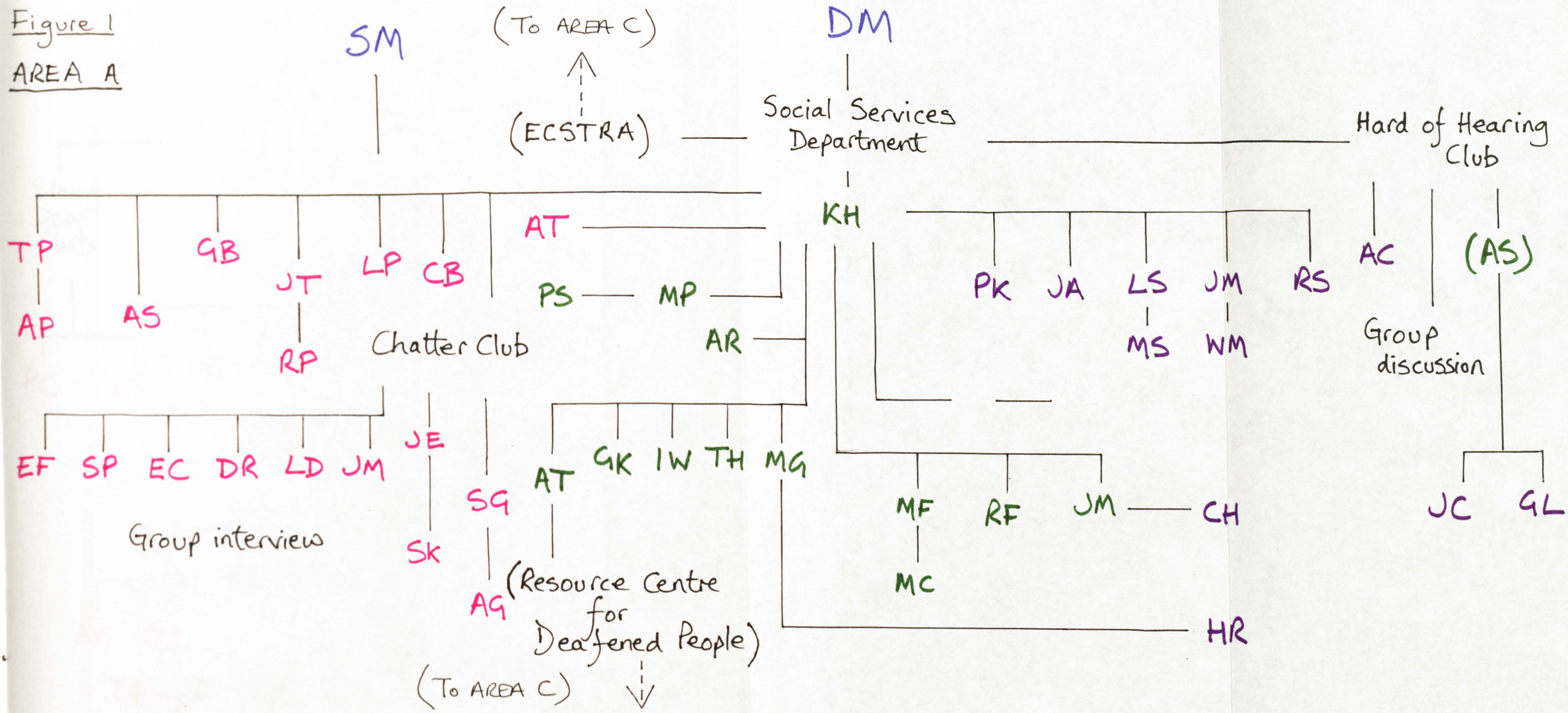
Topics for discussion in interviews: Deafened people / people with acquired hearing loss

First contact with deafness First awareness of deafness	We would like to talk with you about your first contact with deafness, when it was, who it was with, what you can remember about it. We would also like to talk with you about your first experience of deafness, when this occurred, what it was like, what it meant to you.
Information	We would like to talk with you about the kind of information you received about deafness, whether about yours or deafness in general, where this information came from, who gave it, how useful it was.
Significant happenings	We would like to talk with you about the events *you* think are important in your life, what events have been important, why they are important for you, whether they have changed in importance for you over time.
Technology	We would like to talk with you about your experience with technology, what kinds of technical equipment you use, how you use it, what your thoughts are about it, whether it is useful, whether it could be more useful.
Services	We would like to talk with you about how you seek help with some of the difficulties you face, whether you use social workers or interpreters / communicators, how you use them, what people or sources of help you use.

We hope this information will be useful in helping you prepare for the interview. We wish to give you the opportunity to gather your thoughts so that you can talk with us about your experiences in your own way. You do *not* have to talk about any issue that you would rather not.

Figure 1

AREA A



DEAF GROUP	19
Women	10
Men	9
Black	0
Asian	0
White	19

Age range

18–30	31–50	51–70	71+
3	7	8	1

PROFESSIONAL GROUP	13
Women	8
Men	5
Black	0
Asian	0
White	13

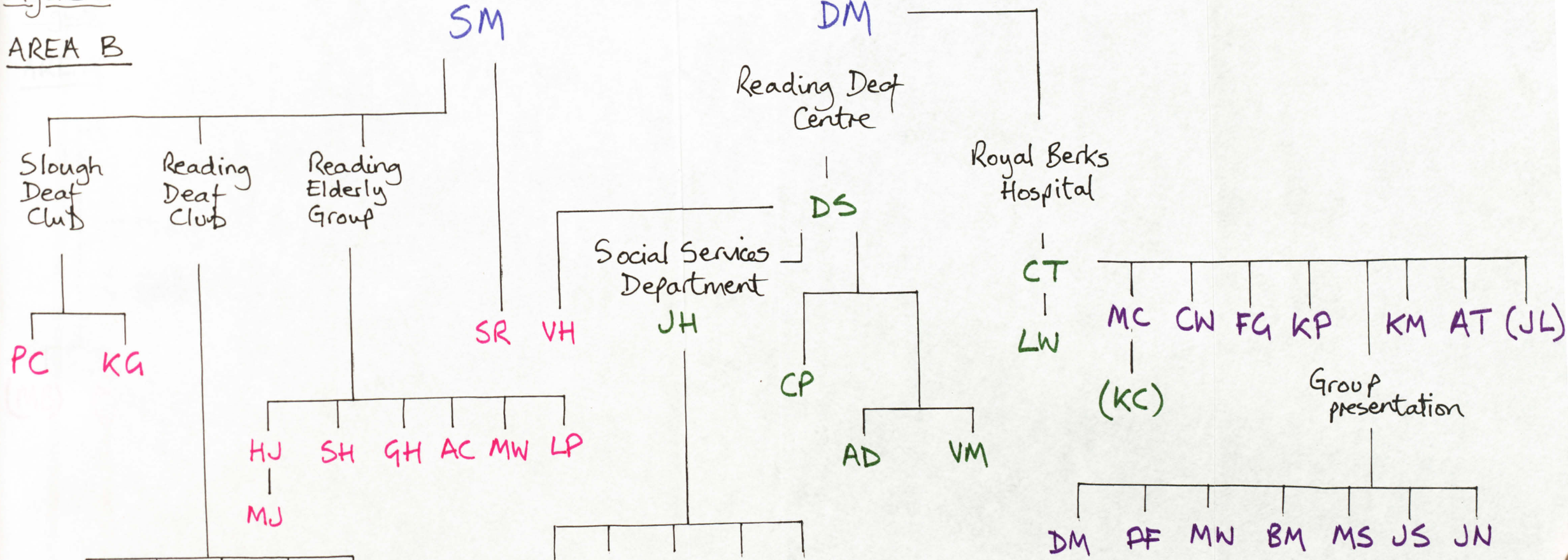
18–30	31–50	51–70	71+
4	5	4	0

DEAFENED GROUP	12
Women	7
Men	5
Black	0
Asian	0
White	12

18–30	31–50	51–70	71+
1	5	4	2

Figure 2

AREA B



DEAF GROUP 16

Women	10
Men	6
Black	2
Asian	0
White	14

PROFESSIONAL GROUP 12

Women	6
Men	6
Black	0
Asian	0
White	12

DEAFENED GROUP 13

Women	8
Men	5
Black	0
Asian	1
White	12

Age range

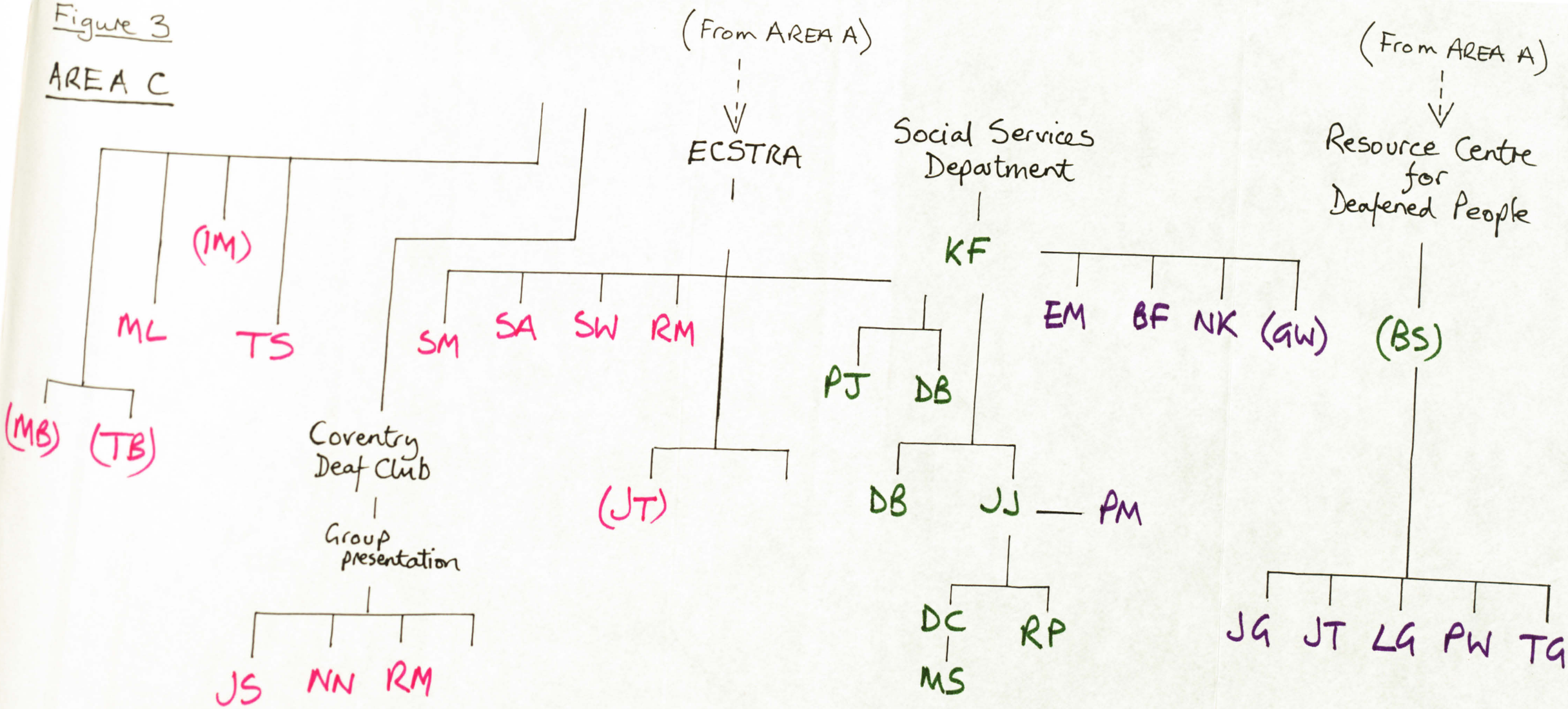
18–30	31–50	51–70	71+
5	4	4	3

18–30	31–50	51–70	71+
1	7	3	1

18–30	31–50	51–70	71+
2	4	6	1

Figure 3

AREA C



DEAF GROUP 9

Women	7
Men	2
Black	0
Asian	2
White	7

Age range

18–30	31–50	51–70	71+
3	5	1	0

PROFESSIONAL GROUP 8

Women	1
Men	7
Black	0
Asian	0
White	8

18–30	31–50	51–70	71+
2	6	0	0

DEAFENED GROUP 9

Women	6
Men	3
Black	2
Asian	0
White	7

18–30	31–50	51–70	71+
1	6	2	0